

INNOVATIVE APPROACHES TO GUARDIANSHIP

Y 4. AG 4: S. HRG. 103-155

Workshop: Innovative Approaches to...

WORKSHOP

BEFORE THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
ONE HUNDRED THIRD CONGRESS

FIRST SESSION

WASHINGTON, DC

APRIL 16, 1993

Serial No. 103-3



Printed for the use of the Special Committee on Aging

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INNOVATIVE APPROACHES TO GUARDIANSHIP

FRIDAY, APRIL 16, 1993

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice.

Staff present: Portia Porter Mittelman, staff director; Anna Kindermann, counsel; and Victoria Blatter, minority professional staff.

WELCOMING STATEMENT OF ANNA KINDERMANN, COUNSEL FOR COMMITTEE

Ms. KINDERMANN. Good morning. I'm sorry for the late start, but I think we can get started now.

I'm Anna Kindermann, I'm Counsel for the Senate Special Committee on Aging, and I just want to welcome you all and thank you all for coming, particularly those who have traveled great distances to be here.

As many of you know, we held the first of what we hope is going to be a series of workshops on guardianships last June; this is the second.

The first forum was a roundtable discussion to see how far we had come from the time that the atrocities in the guardianship system were exposed by an AP story that I'm sure you are all familiar with. I think the consensus was that the States have come a long way in reforming their laws, but there are still a lot of problems with implementing these new reforms.

A role for the Federal Government to play that came out of that discussion was one of forming a resource center for data collection and dissemination. While we are not ready to pursue legislation, we are getting closer as we convene more of these forums and build a record.

Today's forum will discuss innovative approaches to guardianships, in order to get the word out about successful approaches to guardianships that are happening around the country. It's our hope that this forum will lead to a committee print that will provide a compendium of innovative approaches and projects that are occurring around the country.

I want to acknowledge some other staff here, Vicky Blatter, with Senator Cohen's staff. I don't see Diane Lifsey, but she may come in, from Senator Glenn's office. As you know, Senator Glenn has taken the lead on this issue in the Senate.

Before we begin with our distinguished panelists, I want to go over some of the housekeeping details. This room is small, but the acoustics are a little funny. It's an old dining room, so it's not really set up for this kind of forum. We do have microphones on either side, provided by our court reporter, and microphones here so our panelists can stay seated during their presentations. Be sure to speak up when we start the discussion.

I also wanted to point out that there are a number of handouts out front, there is a transcript from our last roundtable in June. There is a handout from the Illinois Protective Service Coalition.¹ There are some other handouts as well that were put out there when I was setting up. There is also some information about a court visitor,¹ a volunteer conservatorship program in Connecticut that was originally funded but was denied funding this year. They are seeking alternative sources of funding to continue what has been a very successful program. Judge Lukens has provided that information, but was unable to be here today.

I also wanted to point out that Desert State Life Management Services was unable to be here today. David Grant, the Executive Director, was invited. Although he could not be here, I wanted to point out that in the April 2 issue of Business Week, there is an article that I believe features that program. I have not seen the article and I'm sorry I couldn't provide it for you today, but wanted you to make note of this program.

One last thing, the National Guardianship Association has an announcement to make, and then we'll begin with our presentations. Doug Kaplan, Legislative Chair for National Guardianship Association.

DOUG KAPLAN, NATIONAL GUARDIANSHIP ASSOCIATION

Mr. KAPLAN. Thank you, Anna.

The National Guardianship Association, which hopefully you have all heard of or soon will hear more about, is sponsoring a legislative breakfast this coming Tuesday from 8 a.m. to 9:45 a.m. We would like to invite you, it's going to be over in the House Rayburn Building, in room 2105. It should be a nice breakfast, we'll have salmon and eggs and bagels and a chance to sit around and talk and get to know everybody a little bit.

This is probably NGA's—one of our first forays into the national arena, and we would like to get to know all of you and welcome you, you meet us, and hopefully welcome us into your local sphere.

I do have some flyers which I will set outside for you if you would like one. If you do plan on attending, if you would let me know or one of the other NGA members that we have here, Charlene Wood or Dorkus Jackson, who is the President of NGA, Michael Casasanto, who is the past President, so we can let the caterers know what to expect.

Thank you.

Ms. KINDERMANN. Thank you.

One more thing—when we do begin discussion, and you want to ask a question, or talk about another program that you're aware

¹ See appendix.

of or involved in, please state your name and the organization you are from, so the court reporter can pick that up.

Now we will begin. We will start with Betsy Abramson, an attorney and the Director of the Elder Law Center of the Coalition of Wisconsin Aging Groups in Madison, Wisconsin, a nonprofit statewide federation of more than 650 organizations that represent and serve Wisconsin's senior population. Her work there concentrates on issues of long-term care for the elderly.

She co-directed a 2-year State justice institute funded by the Judicial Guardianship and Oversight project, which engaged in extensive data collection, development of training programs, videotapes, handbooks for judges, lawyers, and the general public, and improved systems administration through development of judicial bench tools. She currently directs the Wisconsin Guardianship Support Center, which is a statewide legal backup center providing a telephone hotline, technical assistance, development and training materials, and a quarterly newsletter, both of which she'll expand on.

Before joining the Coalition of Wisconsin Aging Group's Elder Law Center, for 9 years she served as Director of the Elderly Team of the Center for Public Representation, also in Madison. She's the author of numerous publications for consumers and professionals on elder law and actually teaches a course on law and the elderly at the University of Wisconsin Law School. She's a frequent speaker at local and national conferences on a variety of elder law topics, and we're very happy to have her with us.

BETSY ABRAMSON, ELDER LAW CENTER, MADISON, WI

Ms. ABRAMSON. Thank you, Anna.

Thank you very much for inviting me. I congratulate the Senate Special Committee on Aging for addressing this issue. With the demographics of increasing number of elderly and those with mental incapacity, this issue is only going to get greater.

For me as an advocate, I think there has been no issue more ethically complex than that of guardianship, where you're not sure as an advocate whether you should rush in to protect someone or you should leave them alone to exercise their rights to autonomy, including the right to continue to make bad decisions. I point to a comment a judge once made in our local community, that in a guardianship proceeding he is often deciding whether to rush in to protect someone or "let her die with her rights on." And as advocates we are often facing the same dilemma.

The fact remains, however, that there are millions of elderly with mental incapacity, and there needs to be some kind of legally authorized decisionmaker. As the 1987 Associated Press series showed, however, sometimes the cure can be worse than the disease. And I think that we must all be mindful of that in our efforts to try to improve the situation.

As some of you whom I've worked with over the years know, we first became involved in guardianship due to concern about the numbers of people who we considered to be languishing, especially in the nursing homes, who didn't have a substitute decisionmaker, didn't have anyone to exercise their resident's rights, and for whom no one was going to speak in making any kind of care decisions.

So at that point, our first reaction was that we needed to get these folks into the guardianship system. We had read our Wisconsin guardianship law, and it looked excellent, it looked like something these individuals could benefit from. At the end of that little foray, however, it was August 1987 when the Associated Press dropped their bomb. And we felt like all of you did, that the guardianship system had really run amuck across the country, and it was not something that we wanted to urge people into. In fact, we concluded that they might be worse off with these so-called "protections" than they were without them.

So we decided to investigate whether Wisconsin was as bad as the Associated Press series reported nationally. We did an informal survey of county Registers in Probate to see what kind of monitoring and follow-up they did. And it confirmed our worst fears. They said "What follow-up?" "What monitoring?" "It's not our job." "The statute says guardians shall report, it doesn't say courts shall make sure they do." So at that point, we decided that our eagerness to get these folks into the guardianship system should be delayed until we cleaned up the system. We decided to approach the whole area with a four-pronged approach, which I have outlined on page 2 of my testimony. First, we wanted to try to avoid the need for guardianship altogether by encouraging people to put in place advance directives, both health care and financial, so that guardianship would never be needed.

Second, we wanted to increase the number and quality of guardians, third, we wanted to reform the guardianship system to ensure more due process in hearings and more good follow-up court monitoring after appointment. Fourth, then and only then, for individuals who did not get advance directives in place, we felt we would be in a position to in fact encourage or urge that more people get into the guardianship system.

Thus, everything we have done over the last 5 years has fit into one of those four compartments. First, in the area of advance planning to avoid the need for guardianship, we have been more involved in health care decisionmaking advance directives than we have in financial, but we're trying to pursue both.

In the financial area, just this past year we started a project modeled after AARP's Legal Counsel for the Elderly's representative payee program. I brought along a sample brochure of the program that we've started in two Wisconsin counties and are also working on the replication manual. It will probably look a lot like AARP's. We're looking for local volunteers in the communities with folks who need some help in bill-paying and money management and are at risk of elder abuse to get some system in place to protect them.

On the health side, we did one project funded by the Legal Services Corporation with law students and subsequently we have had two private foundations support us in efforts with retired teachers as volunteers, where we've gone in, trained the teachers and then on advance directives—the power of attorney for health care law and a newly improved living will.

We have worked with the teachers who then, after they are trained, go out to different places around the counties twice: First they give a presentation, and at the end of the presentation they

pass out a packet of materials to folks that has questions and answers, the forms, step-by-step instructions, a little wallet card that they can fill out and put in their wallet when they're done, saying that they have one. Then they come back the second week, and for those who couldn't do it on their own or didn't get it together to do it on their own or whatever, we actually do the counseling and the witnessing of the forms, which I think is very important.

Everyone who ever gives a presentation on advance directives has had 500 people nodding at them, "yes, yes, yes, it's a good idea," and yet less than 12 percent of the public ever puts pen to paper and does something about it. So I think that getting people in, completing the forms, witnessing the form—getting the document done—is very important in the advance directive area.

Across Wisconsin, we have now been responsible, through these projects for getting about 3,500 more documents in place. It is also important to note that these projects don't have to go on forever in terms of staff. We have now turned the projects over to local county bar associations, who provide the pro bono legal backup to the volunteers, and the volunteers and the pro bono attorneys are continuing by themselves without any additional staff resources.

In the second area of improving the supply and quality of volunteer guardians, we have been putting together training programs for volunteers and for staff to various volunteer guardianship programs. Probably the most innovative thing we've been able to do and that Wisconsin has done—and I urge the Committee to consider doing on a Federal level—is through a small appropriation, through Wisconsin legislation of only \$250,000 a year. There have been requests for proposals out for different county governments or local nonprofits to develop volunteer guardianship programs, seed programs, for programs to get going and get off the ground.

These are programs that are to "recruit, train, monitor, and assist volunteer guardians." And each one of these programs has been doing interesting, innovative different things. Some have recruited more successfully through one-on-one in the church parking lot, some have done it more successfully through radio ads, newspaper ads, whatever. We were awarded one of the grants to develop a statewide legal backup center to all guardians, all people interested in guardianship, and these other individual programs.

As a result of that, for example, we put together a compendium of what we consider to be—in a totally subjective view—the best of these recruitment activities in a booklet called "Finding and Keeping Volunteer Guardians." This has samples of the press releases and the kinds of articles that ran that seemed to work at getting guardians in place. Similarly, we looked through all the projects training materials and put together training materials, and we put together a manual "Teaching and Guiding Volunteer Guardians," that we thought highlighted some of the best of those.

Also through this project, the Wisconsin Guardianship Support Center, which is the name of our grants project, we run a toll-free hotline, which I think is very valuable. We have had over 1,000 phone calls in 2 years from nursing homes, social workers, hospitals, lawyers, concerned family members, judges who call us to read them the law and figure out what they should be doing, ethical dilemmas, end-of-life decisions, jurisdictional issues, etc. Also as

part of the grant we put out a quarterly newsletter that highlights some of the programs around, some of their activities, analysis of the law, reports on the hotline, and addresses some of the questions that have been coming in.

So again, I would encourage the Committee to consider doing some kind of Federal legislation that would have a small appropriation to support innovative pilots in this way.

The third area is improving adherence to the due process protections in court hearings and follow-up by the court post-appointments. This was supported, as Anna mentioned, by our State Justice Institute grant on Judicial Guardianship Support and Oversight. We were, ironically, one of those States that had a great statute. We have what all the other States want. We have an automatic right to counsel, good notice, guardian ad litem, required annual monitorings, availability of temporaries and limited guardianships, statutory preference for least restrictive environment. Every buzz word that's out there, we've got. The only thing that we still have that is really bad, is that we still talk about infirmities of aging, which I think is an ageist term that we should repeal.

However, we weren't convinced that despite those wonderful statutory terms that the actual implementation was any different than any other State. So we, like many States have done recently, undertook a data collection. We went out with a laptop computer, got a researcher from the University who came up with a random cluster sampling, and did file interviews of 600 guardianship cases.

We looked at lots of issues: who initiates petitions, about whom, what's the living status—where is the person—in a nursing home, hospital, still at home? Gender, marital status, whether family is involved? We also looked at the processing. How long does it take? Who is at the hearing? Does the doctor ever show up? Does the guardian ad litem show up? Does the ward show up? Do the proposed guardians show up? And we looked at what the results were of the hearing. We put this all together in a large booklet called "Guardianships in Wisconsin: An Empirical Assessment." Additionally, a report on this will be in the Marquette Law Review sometime this summer.

We found, not surprisingly, that our State is no different than anyone else. In fact, I was on a panel in October with representatives from at least four other States, and our data collection was almost identical, despite the fact that we had very different statutes—ours being the best, others being the worst. We still came up with the same data—how wards were rarely at the hearing, how doctors were rarely at the hearing, how rare it was for anyone to take a look at the individual's functional abilities, how regularly the petitions were granted, how no rights were ever reserved to the wards, etc.

So I think that unlike other States, before first stage efforts of amending the statutes, it's important to underscore the fact that the best of statutory frameworks are meaningless without attention to monitoring the consequent implementation and adherence.

The data collection is important for any kind of reform efforts. When we went on to do training of guardians ad litem under this grant, when we went on to write materials, when we went on to

judicial education, this good data collection provided our foundation; it was the cornerstone of everything we did, we weren't just a bunch of screaming advocates thinking that people were being abused. We knew they were being abused, because the data, the numbers reflected it.

Under that grant, then, we wrote a book called the "Judicial Companion to Guardianship and Protective Services." This is the benchtool that Anna referred to that goes through the statutes—it's like a bench book for judges—but has more editorial comment, more footnotes than the straight law. Because reading the straight law didn't seem to be getting us where everyone seemed to think we ought to be going.

Also in the area of education under that grant, we put together a book called "The Good Guardian," which is a handbook for guardians to use, and all these materials have been provided to every single county court in the State and all the Supreme Court justices. We also put together a book called "Guardianship and Advance Planning Alternatives," that was also sent to all of these courts as well.

Finally, in the fourth area, ensuring individuals in need of guardianship enter the system, we're trying to diminish the attorney general mystique in this area, realizing that in many ways, attorneys have been exclusively handling these cases and have not done a great job. I note that cases will have two attorneys at every hearing—a judge and a guardian ad litem and still people are not satisfied with the results.

So we developed a book called the "Do-It-Yourself Guide to Guardianship and Protective Placement." I should say, parenthetically, it was originally titled "Pro Se Guide to Guardianship and Protective Placement," but one of my staff said "If we're trying to get rid of the attorney mystique, why are you still using the Latin term?"

So I think we all learn something every day doing these things.

We have also been trying to staff several counties in Wisconsin that put together guardianship advisory councils, that have been very useful, comprised of nursing home administrators, nursing home social workers, hospital discharge persons and others. Social workers, lawyers, the judges, advocates are working on trying to address the situation.

One of the major conclusions I've drawn from all this has nothing to do with guardianship at all, and that is that a lot of these problems would go away if we had decent community services throughout the country, and if we had availability of a lot of support services people needed.

But we're stuck with guardianship, in part, because of the institutional bias that we have had in long-term care generally. Even our data reflected this. The great percentage of guardianships corresponded with a medical crisis, at a time someone entered a nursing home, at a time when the situation got so bad that some other health care provider needed to have some kind of legal decisionmaker. But before that point, the individuals were wandering around the community without good services in addition to not being competent and not having a legally authorized

decisionmaker. Those kinds of good preventive health care, as well as preventive legal mechanisms, would go a long way.

In summary our work in guardianship in Wisconsin has been directed at the goals of helping individuals plan ahead to avoid the need for guardianship, and where that's no longer possible, enter into a system that provides strong due process protections for proposed wards, good quality guardianship services and good monitoring. Copies of all the materials that I've talked about are with Anna for anyone who wants to review them.

Thank you.

[The prepared statement of Ms. Abramson follows:]



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Testimony of Attorney Betsy J. Abramson
Coalition of Wisconsin Aging Groups - Elder Law Center
Before the U.S. Senate Special Committee on Aging
April 16, 1993

Thank you very much for your invitation to speak before you today on activities and ideas related to guardianship that we have undertaken in Wisconsin. Given the changing demographics, reflecting significant increases in the oldest of old and the increased incidence of mental incapacity that can accompany advanced age, I believe that your attention to this important issue is well-warranted.

I am a public interest attorney at the Elder Law Center of the Coalition of Wisconsin Aging Groups in Madison and I have been working in the area of elder law for over ten years. During this time, there has been no issue more ethically complicated than that of guardianship. As advocates, the issue of guardianship poses often conflicting goals: preserving and protecting an individual's right to autonomy -- including the right to make "bad" decisions and protecting and even "rescuing" an individual from harm being caused by self or others. This has been poignantly described by one of our local judges presiding over guardianship hearings as the choice between "rushing in to protect someone versus letting her die with her rights on."

We first became involved in these issues in the summer of 1987¹ when we studied the problem of nursing home residents who had entered facilities competent but later became mentally incapacitated. We were concerned that guardianship proceedings were not being started for these individuals and as a result, individuals were remaining in nursing homes without any legally authorized surrogate decision-maker. We ended the summer with recommendations that nursing homes and county social service agencies work together to ensure that guardianship proceedings be commenced for all individuals in need. However, by Fall of 1987, the now-famous Associated Press series, "Guardians of the Elderly: A Failed System," was being printed throughout the country, documenting the serious lack of due process protections throughout the guardianship proceedings and the abuse and neglect perpetrated by court-appointed, inadequately supervised, guardians.

We followed up by conducting an informal investigation of Wisconsin's guardianship system. We conducted surveys of county Registers in Probate and discovered, for example, that a significant percentage of Wisconsin courts did not follow up on guardians who neglected to complete and submit annual reports of guardian of the person and financial accountings -- despite the law's clear directive. Similarly, we heard of numerous incidents where guardians had died and had not been replaced, and no internal county systems to track this existed. And everyone we talked to spoke of the lack of good, qualified guardians.

Put together, we determined that our goal of "getting everyone into the guardianship system" was unwise -- at least until we could be confident that the guardianship system to which we were referring individuals would not result in an equal or even greater deprivation of autonomy. Thus, we embarked on a four-pronged approach to addressing the problem of decision-making by incapacitated elderly:

¹We began work on these issues while still employees of the Center for Public Representation, a Madison-based non-profit public interest law firm, and have continued this work when the entire Elderly Team of the Center transferred to the Coalition of Wisconsin Aging Groups on October 1, 1991, to form the Coalition's Elder Law Center.

- (1) Avoid the need for guardianship by increasing the availability of, and individuals' use of, advance planning alternatives for both financial and health care decision-making;
- (2) Increase the number and quality of volunteer guardians;
- (3) Reform the guardianship system to ensure more due process in hearings and increase court training, supervision and monitoring of guardians once appointed; and
- (4) For individuals without advance directives, and once the system is reformed, ensure that individuals in need of guardianship get into the system.

All subsequent activities have been designed to address one or more of these four goals.

(1) ADVANCE PLANNING TO AVOID THE NEED FOR GUARDIANSHIP

We have been very involved in the area of advance planning for both health care and financial decision-making in the event of incapacity. In the area of health care advance directives, after successfully lobbying for passage of the Wisconsin Power of Attorney for Health Care (one of the broadest and most comprehensive in the country) and amendments to the Wisconsin Living Will, we successfully completed projects involving both law students and older peer volunteers. Following training of the law students/older volunteers, the project offers the general public two-part programs: (1) a presentation on Wisconsin law governing health care decision-making and available advance directives, with hand-out materials; and (2) a second session providing actual one-on-one counseling to assist individuals in completing health care advance directives. To date, we have made presentations to over 8,000 individuals in Wisconsin and assisted in the execution of over 3,500 documents. The projects are now continuing with the legal back-up of local pro bono attorneys.

These important projects, funded by the Legal Services Corporation (for the law student projects) and private foundations (for the older volunteer projects) were developed because while research establishes that high percentages of individuals "do not want to be kept alive like a vegetable," less than 12% ever put pen to paper and make their preferences known. These projects have started to improve that statistic in Wisconsin. Additionally, we have written handbooks on advance directives and, again through the generosity of private foundations, drafted "Do-it-Yourself" packets for advance directives, providing the forms, step-by-step instructions and question and answer segments. Availability of these packets has been widely publicized, translated into Spanish and distributed throughout the aging and health care provider networks.

On the financial side, we have drafted a brochure advising individuals of financial management alternatives to avoid financial elder abuse and we are currently developing volunteer projects under which older volunteers are providing money management and representative payee services to older individuals at risk of self-neglect or financial exploitation.

(2) IMPROVING THE SUPPLY AND QUALITY OF VOLUNTEER GUARDIANS

In January, 1990, staff organized and convened a day-long identification of issues and exchange sessions for corporate and volunteer guardian organizations. In March, 1990, staff organized and conducted two trainings (Stevens Point and Milwaukee, Wisconsin) on guardianship and related issues, including identifying community-based services, voluntary alternatives to avoid guardianship, the role and responsibility of guardians, protective services and future issues.

In August, 1990, staff, under contract with the Wisconsin Department of Health and Social Services (DHSS), organized a day-long program to "showcase" the activities of the first year's grantees under Wis. Stats. sec. 46.977, guardianship grants. This provision of Wisconsin's statutes provides a modest legislative appropriation (\$250,000) for projects conducted by local units of governments and private non-profits to "recruit, train, assist and monitor guardians." Additionally, staff were asked to assist several of the grantees in organizing and conducting the training for staff and volunteer guardians.

Since July, 1991, we have been a recipient of one of the state's grant projects. Our project, entitled the **Wisconsin Guardianship Support Center**, conducts two training programs annually, operates a toll-free telephone line providing information, advice and case consultation to guardians, family members, wards, health care providers, attorneys and local social service staff. We also publish a quarterly newsletter with a circulation of over 2,000 guardians, Registers in Probate, nursing homes, other health care providers, judges and others throughout Wisconsin. The project has also produced standardized statewide materials for recruiting and training guardians.

This legislative appropriation for pilot projects for guardianship recruitment, training and support was proposed by the Wisconsin Department of Health and Social Services based on a recognition that Wisconsin, like most states, experienced a lack of qualified, well-trained guardians. The materials and experiences of the various projects have been shared statewide and used as a model for other counties developing programs. Similarly, the statewide back-up center run by our office, has responded to over 1,000 callers in less than two years, with questions about the need for guardianship, the role of guardianships, court procedures, guardian responsibility and authority and alternatives. The quarterly Newsletter is widely disseminated and serves as an inexpensive efficient means of communicating significant information and developments in guardianship law.

I encourage the Committee to consider sponsoring federal legislation and an appropriation that would allow for such innovative pilot projects in all states, similar to that which you passed for Medigap information, education and counseling, which also went to the states.

(3) IMPROVING ADHERENCE TO DUE PROCESS PROTECTIONS IN COURT HEARINGS AND COURT FOLLOW UP POST-APPOINTMENT

Our colleagues in other states and national offices often point to Wisconsin as having a guardianship statute to emulate, one replete with significant due process protections for proposed wards. These include: mandatory notice for hearings; appointment of a guardian ad litem; the right to defense counsel (publicly funded if indigent); the right for independent medical examinations; the right to cross-examine witnesses; a presumption that the proposed ward be present at the hearing; provisions for the hearings to be held in a location convenient to the proposed ward; the right to jury trial, the right to "least restrictive environment," for placements, temporary and limited guardianships; required annual reports by both the guardian of the person and guardian of the estate; and independent annual court reviews of all individuals protectively placed.

Therefore, unlike other state's first stage efforts of amending their statutes, we pursued the area of increasing due process protections with a recognition that while the statute already contained much of the required due process, it was simply not being followed. The importance of this point cannot be overstated: the best of statutory frameworks are meaningless without attention to monitoring the consequent implementation and adherence.

Much of the work in this area has taken place under our **Judicial Guardianship Support and Oversight Project**, funded by the State Justice Institute. This project was developed with the input and advice of the Director of State Courts, representatives of the Wisconsin judiciary, members of the private bar, consumer groups, volunteer guardians, Wisconsin Department of Health and Social Services staff and law school faculty. The project involved three components:

- (1) Data Collection undertaken by a representative cluster sampling of over 600 actual guardianship files throughout the state to determine the characteristics of petitioners, proposed wards, proposed guardians, the nature of the proceedings and outcomes (e.g., whether protective placement was also included, whether temporary or permanent, full or limited guardianships, etc., length of hearing, number of witnesses present and testifying, etc.);
- (2) Education done through project development of consumer handbooks: Do-It-Yourself Petitioner's Guide to Guardianship and Protective Placement, The Good Guardian, and Guardianship and Advance Planning Alternatives, training programs for Registers-in-Probate, guardians ad litem, and trial court judges; and
- (3) improved systems administration through development of court registries for powers of attorney for health care and financial matters, court forms for use at hearings and the Judicial Companion to Guardianship and Protective Services, a benchtool designed to assist judges in enhancing due process at court hearings.

This portion of the project demonstrated the significant divergence between law and practice. Reality, as demonstrated by our data collection, proved that our system, like that of many other states', does not comport with the law or its philosophical underpinnings. Thus, even the best revised statutory frameworks, without any provisions or plans for on-going monitoring, will not, in and of themselves, guarantee improvements.

This type of project is also one that is well worth replication. Clearly, before any reforms can be identified, conceptualized and proposed, significant data is needed about the current experience. Our project's careful, empirically sound data collection and report provided the basis for all subsequent educational efforts and reform proposals. Thus, the data collection was important in establishing credibility as to the need for reforms, both statutory and adherence to statutes currently existing. Judges, other court staff and private attorneys were more willing to recognize and accept the current system's shortcomings when they "saw the numbers."

Project-developed judicial benchtools directly addressed various issues where the actual practice diverged from the law. Similarly, training program agendas, (targeted for Registers in Probate, judges and practicing attorneys) were designed to address specific areas that the data had identified as inconsistent or in direct contradiction with the law.

Thus, I encourage the Committee to consider national reporting on guardianship issues, of the types of topics covered in our research. This information should then be shared with judges, court personnel, private bar involved in guardianships, state court staff, advocacy groups, continuing legal education and judicial education agencies and others.

(4) ENSURING INDIVIDUALS IN NEED OF GUARDIANSHIP ENTER SYSTEM

In this area, we have also engaged in several activities. First, we drafted, printed and distributed the Do-it-Yourself Petitioner's Guide to Guardianship and Protective Placement, enabling family members and other non-attorneys to file petitions for guardianship without incurring legal fees. We have also conducted training programs for nursing home social workers, case managers and others teaching them about the guardianship process and how to file and proceed with guardianship petitions.

We have also staffed several counties' Guardianship Advisory Councils and facilitated in-services for counties attempting to develop protocols and procedures for hospitals, nursing homes, protective services and courts to ensure that individuals in need of protection enter the guardianship system.

Similarly, we regularly work with the Wisconsin Registers in Probate Association, the State Bar's Continuing Legal Education Department and others to improve court access for these protections. Additionally, through questions we have received on the Wisconsin Guardianship Support Center Hotline, we have identified numerous weaknesses and/or ambiguities in our Wisconsin statutes regarding jurisdictional issues, funding issues, responsibility to file petitions and other issues that we are working to resolve with the state's Attorney General and the Wisconsin Legislature.

We have recently been awarded a grant to research, investigate and propose changes to Milwaukee County's protective services system. The major focus of this effort will be to correct Milwaukee's problems in providing needed guardianship and protective services to vulnerable older adults. This project will involve interviewing scores of individuals involved in the system, analyzing the data on Milwaukee's guardianship system and the budget for protective services, studying other counties' (and states') systems and drafting a report making recommendations for reforms, including any legislative changes and/or costs thereof. While Milwaukee County, being Wisconsin's largest, is experiencing the largest problems in coordination and provision of services, its actual problems are not unique; therefore, we anticipate being able to use the "blueprint" ultimately developed to help resolve other counties' problems in these areas as well.

In sum, our work on guardianship in Wisconsin has been conducted with the goals of helping individuals plan ahead to avoid the need for guardianship, and where that is no longer possible, enter into a system that provides strong due process protections for proposed wards and quality guardianship services.

Copies of all materials referenced in my testimony as well as other materials produced under the various projects described have been provided to Committee Staff. Again, I very much appreciate the opportunity to present this testimony to your committee today and hope that my comments have been helpful to you in your work.

Ms. KINDERMANN. Thank you, Betsy.

Our next speaker is Teresa Barton, with the Cathedral Foundation. She's actually the Director of the Community Services Division there, Urban Jacksonville. I also would like to acknowledge Theresa Bertram, who's here in the second row, in the red suit. She is the Chief Executive Officer of the Foundation.

Teresa Barton's primary responsibility as Director of the Community Services Division includes providing for the development, administration, and management of all programs under this division. She's responsible for administering the guardianship education program for the Fourth Judicial Circuit of Florida, and her prior experience includes a variety of social service positions. She is an honors graduate from Marshall University, and has taken graduate courses at West Virginia College for Graduate Studies. We welcome Teresa Barton.

**TERESA BARTON, DIRECTOR, URBAN JACKSONVILLE
CATHEDRAL FOUNDATION, JACKSONVILLE, FL**

Ms. BARTON. Thank you.

That was a wonderful segue, really, because I do community services, and I really believe you made my point.

I am Terry Barton, and I do represent Urban Jacksonville, and on behalf of Urban Jacksonville, on behalf of the Cathedral Foundation, I would like to thank this distinguished committee for the opportunity to be included in this workshop on innovative approaches to guardianship.

The Cathedral Foundation is a nonprofit service organization. We provide residential care, nursing home care, and a variety of community services to the elderly in north Florida. The community services division is Urban Jacksonville. And Urban Jacksonville delivers, in addition to the protective counseling services program, the Meals-on-Wheels program for north Florida, we have the largest Meals-on-Wheels program. We operate 800 meals a day.

We also have supportive services program for 1,200 frail elderly persons through our Community Care for the Elderly program that's funded by the State of Florida. We provide the mandatory training that's required for all of the guardians now appointed in the Florida Fourth Judicial Circuit. We operate a very small corporate guardianship program. And we also sponsor, in conjunction with AARP, a representative payee program. We basically sponsor and coordinate this volunteer activity.

All of our programs focus on providing or restoring and maintaining independence for those people that we serve. Our programs are funded by Federal, State, and local agencies. Also corporations, churches, individual contributions. In other words, we're multifunded and grant subsidized and always scrounging around for grant sources.

Today, of course, we want to discuss the protective counseling services program that we operate out of community services. Protective Counseling Services is a unique program. I think it was certainly unique at its inception, because it's whole intent was to divert or delay guardianship. We have been doing this for nearly 15 years. We provide, we have attempted to divert guardianship by providing daily money management, case management, and any

other advocacy services that would facilitate independence for our clients, while assisting in preventing more intrusive methods of intervention.

Approximately 2,500 people have been served by this program since its inception. The program is structured to provide intensive client-oriented services, and we operate like this. First, persons accepted into the program are initially assessed and we do an assessment of their living situation. That includes an evaluation of their past and current medical status, their cognitive ability, their financial circumstances, and any deficits that they might have in their activities of daily living. And it's from that assessment that we develop a case plan in conjunction with the client. The case managers attempt to address the individual's needs in this care plan.

The plan will include budget planning, financial counseling, and any other referral to any other appropriate services that the client might need in order to maintain their independence. The client must agree to the services they receive, and they have to understand that their participation is voluntary in this program. Because autonomy and a sense of choice are the critical elements of the Protective Counseling Services program.

The program utilizes voluntary legal instruments, like a power of attorney or representative payee designation, in order to transact the business on behalf of that client. The functions of the daily money management component include paying the client's bills, negotiating with creditors to restructure debts, processing health care benefits and claims forms, and any other financial or legal services that are needed. We are not financial experts, and we don't profess to have financial expertise. What we do, I think, and do well, is we are networked into the resources in our community that can provide that expertise. So we have no problem in referring clients and getting clients those kinds of services.

The clients, the actual funds that we handle on behalf of the clients, are kept in a checking account that is maintained by Urban Jacksonville. Normally, the funds that are required to pay their monthly expenses are directly deposited through the representative payee program, direct deposited into the accounts. We don't maintain funds in excess of what it takes to manage their daily money management. We're not financial planners, we don't do investment planning, those kinds of things. If they need those services, we refer them.

The case managers don't have access to our clients' bank accounts. Rather, the way the process works is, the case managers actually do the budgeting, and they do requests that are prepared and submitted to our financial management counselor, who then authorizes from the accounts payments to be made on behalf of the client.

And as Betsy very clearly explains, I think the big problem in the community, why the diversion program works, is because we handle that immediate crisis. Most of our clients and participants are referred to us as a result of a crisis situation, a multifaceted crisis situation. Their electricity bills may have gone unpaid, they have had their utilities disconnected, their taxes are in arrears, they may have had their property in foreclosure, and they could have serious problems with creditors and banks.

In addition to that, there is often a medical crisis that has either precipitated this or in some way been involved. The crisis could be caused by memory impairment, loss of some cognitive function associated with a disease, or sometimes it's just precipitated by the loss of a spouse or a child that they relied upon to handle their daily affairs.

A great deal of time and effort is spent initially with these clients in stabilizing their living situation. I really can't overemphasize that. I think the crux of why the case management function is because early on, those case managers spend an inordinate amount of time trying to get the situation stable in order to avoid placing the individual or removing the individual from their home. It is not uncommon for my case managers to literally have grocery bags full of bills and receipts and things that have been unattended to by our clients for a long amount of time.

And of course in addition to handling their daily money management needs, the case managers also have to coordinate the other services and needs of the clients, such as medical appointments, their homemaker services, their transportation services, home repairs, and Meals-on-Wheels if it's necessary. In other words, they are implementing a comprehensive service plan. And that's the critical component of why PCS works, is that it really approaches the problem comprehensively. It's that overlay of social services, along with the financial and legal intervention, if necessary, that kind of pulls it all together. It restores the stability and allows the clients to have some semblance of independence.

The participants in the program, what are our participants like? Well, they vary greatly. There is not a typical participant. But some of the characteristics they all share is that they almost all live alone, and they are all low or moderate income, they are all in their seventies. Our median age is over 72. And of course they are all experiencing some degree of difficulty in managing their daily finances and arranging for their daily affairs.

In order to receive protective counseling services, the individuals must agree to the daily money management component, and they must agree to accept this assistance voluntarily. Because of that, the volunteer nature, it's really an excellent tool for diversion for clients that have some functional impairment, but they understand that they need help and they are willing to accept this.

I think that many people realize, especially the elderly, realize that they are not functioning perhaps well in a certain area, but we have so many biases that what happens with the elderly is that they get very defensive about their functioning, because they are afraid they are going to lose their independence if they admit that they are having some difficulty in managing. Then the next step is someone's going to want to put them in a home, or someone is going to take their independence away and have them declared incompetent.

So I think it's very reassuring to our clients, our attempts to assist them always to make their own decisions. That's very important. And there are instances, of course, where we cannot be successful, where diversion is not going to work. Individuals who lack any capacity to consent, or individuals who are unwilling to accept the services voluntarily are not going to be accepted into the pro-

gram. And in those instances, guardianship may be the only method of intervention.

So our program does have a component of guardianship. We never initiate the incapacity proceedings, however, because we feel that would be a conflict of interest to do so. But we can act as a corporate guardian of last resort, if there is no one else available for the individual to be their advocate. Because we really seek, the essence of our program, is being an advocate on behalf of our clients.

Interestingly enough, our guardianship clients receive essentially the same services as the client in the voluntary program, with the only addition being the legal reporting and monitoring process of guardianship. Our voluntary program is monitored by our various funding sources, as well as we have an independent CPA audit that we submit annually.

And in the past 15 years, we have served less than—well, we served 32 people in our guardianship program, and we have assisted in securing perhaps another 25 to 30 people, guardians. If there is someone out there who is able and willing to be the guardian, we do not want—what we will do is assist them with the training and the education, and in developing a plan for their ward, which is the crucial part of the services. We also assist in training guardians and providing information to them about how to develop good care plans for their wards.

The Protective Counseling Services program is currently serving 102 voluntary clients and 16 wards. All of our clients are encouraged to participate in decisionmaking and planning for services and choices in life style preferences.

In our 15 years of operation, a lot of things have changed in Florida. Guardianship still remains the most intrusive form of legal intervention, however. But Florida has completely revised its guardianship statute and it's actually codified the principle of guardianship as a last resort. Lots of progress, lots of innovation has been made in the area of law that refers to advance directives.

These instruments, like durable power of attorney, designation of a health care surrogate and the living will, have allowed individuals to determine how to act in their behalf. And we encourage our participants to make advance directives. Taking these steps may be the most simple and effective way that they can avoid guardianship proceedings.

But even with that, even with the advance directives, we still feel there is always going to be a need for guardianship and guardianship diversion services. Not only because most people won't do this, unless someone prompts them to take pen in hand and do it, but also because it relies on the thing that makes it work, is the advocate, the person. And in our experience, a lot of our clients, they don't have an advocate. What is missing in their lives is that person that would do that or provide that service for them.

So for those people, they are always going to have to rely on a formal network of services that will deliver any advocacy that they are going to receive. And we feel that our program has demonstrated that through the services we provide, and in working in close cooperation with the other programs in our community, that formal service programs can include that component. Our program

has been able to provide frail elderly people living in Duval County, Florida, with advocacy efforts that affirm the dignity of the individual while resolving the crisis and maintaining their independence. We really believe the success of this program has been in the cooperation and the investment that all the agencies in our community have made in meeting this need for the elderly.

And I guess I would just finish by saying I hope this committee will encourage, in some fashion, the support of advocacy services in a programmatic way. Because I truly believe that's a very critical component of providing good guardianship and guardianship alternatives.

Thank you.

[The prepared statement of Ms. Barton follows:]

WRITTEN STATEMENT

PROTECTIVE COUNSELING SERVICES PROGRAM
URBAN JACKSONVILLE, INC.
JACKSONVILLE, FLORIDA

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Urban Jacksonville and its eponsor, the Cathedral Foundation, thank this distinguished committee for the opportunity to be included in its series of workshops on innovative approaches to guardianship. The Cathedral Foundation is a non-profit, service organization which provides residential care, nursing home care, and various community services to the elderly in north Florida.

Urban Jacksonville delivers vital community-based social services to elderly individuals throughout Duval County, Florida. In addition to its Protective Counseling Services program which will be detailed in this presentation, Urban Jacksonville operates the largest Meals on Wheels program in north Florida, serving 800 meals per day, and delivers home based support services to 1,200 frail elderly persons through the Community Care for the Elderly project funded by the State of Florida. Urban Jacksonville provides the mandatory training required for all guardians appointed in Florida's Fourth Judicial Circuit, operates a corporate guardianship program, and participates in the national Work/Family Elder Directions program assisting employees of participating corporations in locating appropriate resources for aging relatives. All of these programs provide services focused on restoring or maintaining the independence of those served. Programs are funded by federal, state, and local agencies, corporations, churches and individual contributions.

Urban Jacksonville has been invited here today to discuss its Protective Counseling Services program.

The Protective Counseling Services program (PCS) is a unique program which attempts to divert or delay guardianship. For nearly fifteen years, Protective Counseling Services has provided daily money management, case management, and other advocacy services to facilitate independence for its clients while assisting in preventing more intrusive intervention methods. Approximately twenty-five hundred people have been served by the program since its inception. The program is structured to provide intensive client-oriented services and operates in the following manner:

Those accepted into the program initially receive a thorough assessment of their living situation which includes an evaluation of past and current medical status, cognitive ability, financial circumstances, and activities of daily living.

From this assessment a care plan is developed by a case manager, in cooperation with the client, which addresses the individual's needs. The plan includes budget planning, financial counseling and referral to other appropriate resources as necessary. Clients must agree to the services they receive and understand their participation is voluntary. Autonomy and a sense of choice are critical elements of the Protective Counseling Services program.

The program utilizes voluntary legal instruments, like a power-of-attorney or representative payee designation, to transact business on behalf of clients. Functions of the daily money management component include: paying client bills, negotiating with creditors to restructure debt repayment, processing health care benefits and claims, and obtaining other financial or legal services as needed.

Client funds are kept in a checking account maintained by Urban Jacksonville. Normally, the funds required to pay monthly expenses are directly deposited into that account through a representative payee arrangement with Social Security. Case managers do not have direct access to client bank accounts, rather, a request is prepared by the case manager and submitted to the financial management counselor authorizing the payment of client expenses.

Most program participants are initially referred as a result of a crisis situation -- electricity bills have gone unpaid and utilities are disconnected, taxes are in arrears and property is in foreclosure, or there are serious problems with creditors or banks. Often, the crisis is caused by memory impairment or a loss of cognitive function associated with a disease. Sometimes problems are precipitated by the loss of a spouse or child relied upon to handle their financial affairs.

In addition to handling the daily financial management needs of program participants, case managers also coordinate any other service needs such as medical appointments, homemaker services, transportation, home repairs, Meals on Wheels meals, etc. Implementing a comprehensive service plan is a critical component of the Protective Counseling Services program. It is the overlay of additional social services which alleviates the crisis, restores stability, and allows clients to become or remain independent.

It is the ability of the Protective Counseling Services program to respond to people in crisis and in danger of losing their independence that makes our program a guardianship diversion program.

While program participants and their circumstances vary greatly, most live alone, have low to moderate incomes, and are over 72 years old. All experience some degree of difficulty in managing their finances. To receive protective counseling services, individuals must agree to daily money management and be willing to accept the assistance the program provides voluntarily. The voluntary nature of our program makes it an excellent diversion tool for clients with some functional impairments.

Of course, there are instances where diversion will not be successful. Individuals who lack capacity to consent, or will not accept voluntary services cannot be accepted by the program. In those instances, guardianship may be the only method of intervention. The program does not initiate incapacity proceedings, however, on a very limited basis, Urban Jacksonville serves as a corporate guardian for clients who have no one to represent them.

In the past fifteen years, Urban Jacksonville has served as guardian for thirty people and assisted in securing guardians for perhaps another twenty-five to thirty people. The program has also assisted in training guardians, as well as providing information and assistance to them, on an informal basis.

The Protective Counseling Services program is currently serving one hundred and two voluntary clients and sixteen wards. All clients are encouraged to participate in decision making, planning for services and choices in life style preferences.

While guardianship still remains the most intrusive form of legal intervention, Florida has completely reversed its guardianship statute codifying the principle of guardianship as a last resort. Progress has also been made in the area of the law referred to as advance directives.

Advance directives are legal instruments individuals use to prepare for the possibility of future incapacity. These instruments, a durable power of attorney, designation of a health care surrogate and/or a living will allow an individual to determine who will act on their behalf. Taking these steps may be a simple and effective way to avoid more intrusive guardianship proceedings. However, even with these instruments, which are expected to be more widely used in the future, the need for guardianship and guardianship diversion services will undoubtedly continue to rise.

Advance directives can be effective only if there is a designated advocate for the elderly person. It has been the experience of the Protective Counseling Services program that some individuals simply do not have anyone in their lives to act in this role and must rely on a formal network of services in order to receive advocacy and assistance.

The Protective Counseling Services program has demonstrated that daily money management and guardianship diversion services can be part of the formal network of services for a community. By working cooperatively with the legal community, financial institutions, and other social service agencies, Urban Jacksonville has been able to provide the frail elderly in Duval County, Florida, with advocacy efforts which affirm the dignity of the individual, resolve the crisis, restore independence, and offer ongoing support and stability. It has been this cooperative effort and concern for our elderly community members that have truly been the success of our program.

Ms. KINDERMANN. Thank you, Teresa.

Next we have Michael Casasanto, the Director of the Office of the Public Guardian and Co-Director of the Institute for Health, Law and Ethics, at the Franklin Pierce Law Center. He has published and lectured extensively in the areas of assessing capacity and the ethics of surrogate decisionmaking. He's a founding board member and immediate past president of the National Guardianship Association.

He was selected to participate in the 1988 Guardianship Symposium as well as the National Conference on Court Related Needs of the Elderly and Persons with Disabilities held in February 1991. He developed, along with the educational coordinator, the individual functional assessment tool which is an evaluation that is used to help determine the legal incapacity, as well as a model code of ethics for guardians presented at the second annual health symposium in 1989, and subsequently endorsed and adopted by the National Guardianship Association.

He's a frequent consultant and advisor to States in their revision of guardianship law. He has over 15 years of experience in working with the New Hampshire courts in the area of guardianship and alternatives. He has a J.D. from Franklin Pierce Law Center.

Michael.

MICHAEL CASASANTO, EXECUTIVE DIRECTOR, OFFICE OF THE PUBLIC GUARDIAN, CONCORD, NH

Mr. CASASANTO. Thank you. I appreciate the opportunity to be here today.

One of the interesting things, when I sit and hear people talk about the genesis of their programs, is that we all kind of developed in a vacuum. And I think until recently forums like the National Guardianship Association and certain conferences, that people got together and started talking about what they were doing. And it's been very interesting to hear how people have faced the same sorts of problems, how they have adopted the same sorts of values, but how they have approached the problem differently and have come up with different answers. And I think there is a lot to learn by looking at how different States have developed over the years.

We got started in 1978. I was involved with working with children primarily, and other legal aid related issues. And at that point, the folks who ran the Institutional Law Project, New Hampshire Legal Assistance brought a case, called *In Re Gamble*, which resulted in the Supreme Court of the State deciding that it was the responsibility of the State of New Hampshire to provide independent guardians for people who were incapacitated and who were residents of State institutions. And that had to be with State funding at the time.

Everyone was terrified of public guardianship and it was interesting that folks at Legal Assistance were the ones who were bringing the case and kind of prompted all that. Everyone was just full of trepidation concerning what would be the result of the public guardianship program in the State. To make it a little easier, at the same time, in 1978, there was complete overhaul of the State's guardianship laws.

And like Wisconsin, all the buzz words are in there. There were some early attempts at requiring a limited guardianship. There were strong attempts at reforming procedural due process, for example, requiring counsel, requiring the ward's presence at the hearing, enhancing the burden of proof to beyond a reasonable doubt, so on and so on, full rules of evidence.

It was really something to see at the beginning, because it went from really a medieval process that in fact is called an "inquisition," in which a panel of three professionals, "inquired" as to the person's incapacity, would then make a recommendation to the probate for a judge, who would typically rubber stamp it.

We went from that to in essence a criminal-like proceeding for guardianship, and the turnaround was tremendous. I think part of that was to ease some of the fears of the implementation of public guardianship system in New Hampshire. And the system started out relatively small. The idea was to create a semi-autonomous State agency that would provide guardianship to people who were residents of State institutions, who like most public guardians, had neither friends nor relatives to act in that capacity, or have no friends nor relatives who qualify to act in that capacity.

After about 2 years of doing that, and I was one of the four original public guardians appointed, we were feeling continuously that we were in a conflict of interest situation. Despite developing policies pursuant to which we would not bring guardianship petitions, we would not be involved in cases at all prior to the actual appointment, we would not—even such things as having offices on grounds of State institutions, we would try to be seen by our clients, by our wards, as an independent decisionmaker, we still felt there was some conflict of interest involved, and there is no way to completely avoid the issue of conflict of interest, because the money has to come from somewhere.

Nevertheless, we tried. We took the next step, which was reforming the State legislation, and amending it to allow the State to contract for the provision of public guardianship services. The idea was to allow the State to satisfy its legal mandate by having an agency or agencies, and—there are actually two—contract with the State. Now, we devised legislation so that the agency that was to contract with the State had to be approved by the Supreme Court, and the idea there was to help ensure that the State would not just give the contract to the lowest bidder, or contract with the most compliant guardianship office. And we tried to build as many safeguards as possible in there.

But the other thing we did at the same time was we made a conscious decision that this Office of Public Guardian Corporation would be allowed to provide other services to clients, other services in the area of surrogate decisionmaking, guardian ad litem service, powers of attorney, various money management services and so on. However, the State, the agency, by statute, was specifically prevented from providing direct services to wards, and that was another attempt to refrain from this conflict of interest issue that we saw.

The agency could not provide counseling, clinical services, treatment services, housing, anything that was a direct service and otherwise available to the ward. And we really kind of took the idea

that the legal fiction that a guardian stands in the shoes of the ward to its logical conclusion, and that is the guardian was and is a consumer of services on behalf of the ward, and as such, cannot provide any services.

To the extent that even though many of us are lawyers in our office, when a client has a legal problem, if they are indigent they will go to Legal Assistance. If they are not indigent, an attorney would be hired, just like any individual who has a legal problem who is not under guardianship.

The other decision we made was that this corporation would be able to provide services to not only indigent people, but to whoever it wanted to provide services to. And in that sense, we tried to develop what we consider professional models of providing guardianship services. We put the office in the marketplace and competed with the bar association, with individual law firms, with banks, trust companies, and other people that were providing financial management services and guardianship services to clients.

The idea there was to try to have the highest quality services to our indigent clients, getting out of—and this isn't meant in a demeaning way—but getting out of a social services mentality in the sense of always having to be hand-to-mouth in providing services, and really being professionals and seen as professionals. As a matter of fact, at this point, courts will call on us most likely when there are really awful cases of abuse or exploitation of elderly people or developmentally disabled people, mentally ill people. Because we have developed the reputation for having the expertise to deal with those kinds of cases.

And in that sense, we have staffing that includes not only lawyers but social workers, people with medical backgrounds, nurses and what-not. And we try to provide a complete approach to professional decisionmaking services on behalf of the wards.

Now, all of this was with the idea that public guardianship is certainly not the preferable way to go for anyone, but it is a necessary thing in some cases. And we, I, was presumptuous enough to feel that if somebody's got to do it, it might as well be people who had the right values. So with that rather self-serving statement, we jumped into providing these services.

What I will just mention now briefly is, I would like to set forth a couple of guidelines for the provision of the guardianship services and end with that. Because all this developed in a vacuum, there is very little out there in the way of experience based models for providing public guardianship services. I think we're first starting now to talk to each other, as I said earlier, about these issues.

But what I had mentioned previously is that the public guardian should really be a leader in the area of providing guardianship services, should be highly professional, should make sure those buzz words in the statute are implemented, should be the people, the office that has the high level of expertise and that trains the judges, the attorneys, the social workers, and the people in the State that provide guardianship services. We have worked a lot at developing, for example, models, model pleadings for guardianship petitioners, model orders so that courts could grant limited guardianship whenever possible.

As a matter of fact, in New Hampshire now, well over 90 percent of the cases are limited. Plenary guardianship is relatively rare. The statute requires orders to be individualized, and as a matter of fact they are. We have worked hard at helping judges to recognize cases when guardianship should be limited. We have worked hard with people who bring petitions on behalf of hospitals and other people in the probate law field to make them understand that it's easy to bring a limited guardianship petition, that it doesn't take more work, it may in fact take less work.

And we also train people who are involved with representing proposed wards in the areas of limited guardianship, and that goes on to a number of different alternatives to guardianship. We have been very involved in training around the State, which isn't to say that we hold all the expertise in the State; it's simply that we've tried to take a leadership role.

Now, we've tried to also balance that with maintaining a very low public profile. We adopted a philosophy that guardianship is certainly not something that should be pushed, that should be advertised, that should be presented, and any way is a panacea for resolving problems. And it's a difficult line to walk, to try to present yourself as an agency or an office that has considerable expertise in this area and are professional decisionmakers while at the same time saying we're going to very much lay back here and try to push services away from us.

We also try to push, or try to refrain from acting as a drain on funding for direct services to indigent people. And in that sense, the idea of providing services to nonindigent people on a fee-for-service basis helps. We've been able to provide very fiscally responsible services by charging people who can afford to pay for our services and thereby stabilizing the sort of pro bono activities that we can maintain.

We intentionally do not seek funding for guardianship services from any other agency than the State. We do not accept United Way funding or any outside funding at all to provide our services. We feel that it's the State's responsibility to provide guardians for people who are indigent, and in fact that's who should pay, not the United Way and not the charitable fund or whomever.

Again, it's kind of a hard-headed approach, but that's what we decided to do. And in that sense, we looked to the public defender as a model for public guardianship. The same idea, a person has a right to a lawyer, if accused of a crime, under the law. And in the same way, a person has a right to a guardian. It's the same line of thinking, and the guardian must be as independent as the attorney for the indigent criminal is, and must be as free from influence as possible.

And even to that degree, in our State contracts there are clauses in which the State is only entitled to have audits from us to see that we use the money for services to clients, but are not entitled to any other programmatic reports or activities. They recognize that the office is a fiduciary, and at times we make decisions that the State is not exactly in agreement with, and even though we are using their funds, we may have to take an adverse position.

And over the years, that's worked out well. We've for example acted as plaintiffs in the Laconia State School case, which was a

case that closed down the State institution for the developmentally impaired in New Hampshire. In fact, New Hampshire is the only State, without any institution for developmentally impaired people. And we have acted in a number of ways to try to create positive change. And in that sense, as scary as public guardians may be, I think a public guardian working with a good public advocate is probably one of the best ways to create change for the better for a lot of poor people who may not have any ability to speak for themselves.

The other guideline is the adoption and actual use of standards and codes of ethics in providing guardianship services. I really think that one has to wear their values on their sleeve in this area. And I think in that sense, adopting a code of ethics which in our case embraced some of the principles that were in the guardianship law, such as the least restrictive alternative; the idea of substituted judgment whenever possible; the idea of guardians having to terminate guardianship when that's possible; and, the idea that guardians should always seek to limit guardianship whenever possible. Having those guidelines right out there, having them on the table, is very important for public guardianship agencies. It provides for a higher level of accountability, allows for some consistency in decisionmaking, and I think allows for enhanced quality in decision-making.

I don't know if we have any copies today, but the National Guardianship Association has developed a code of ethics, and has promulgated some standards in this regard, and they are available from the Association and might be interesting to look at.

I think I'm just going to leave it there. Thank you for your time.
[The prepared statement of Mr. Casasanto follows:]

Innovative Approaches to Guardianship

United States Senate Special Committee on Aging
Dirksen Senate Office Building

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Statement by Michael D. Casasanto,
Director of the Office of Public Guardian, Concord, NH
and Co-Director of the Institute for Health, Law and Ethics,
Franklin Pierce Law Center, Concord, NH

I. Introduction

For fifteen years the State of New Hampshire has had a reputation for having a model guardianship statute and also for providing "public" guardianship services in an effective and fiscally responsible manner. What follows is an overview of the history of guardianship in New Hampshire followed by a description of the Office of Public Guardian, Inc. of Concord, New Hampshire. The final section will consist of a set of principles and guidelines for the provision of public guardianship services.

II. Historical Overview

The New Hampshire Office of Public Guardian was legislated into being in 1978. The legislation (which coincided with a complete overhaul of the State's guardianship laws) was "prompted" by the case of In Re Camble in which the New Hampshire Supreme Court decided that it was the responsibility of the executive branch of state government to provide guardians to legally incapacitated residents of the state's institutions who had neither friends nor relatives able or qualified to serve as guardian. The two probate judges in the counties where the institutions were located worked in conjunction with the Guardian Advisory Council to appoint four individuals to be Public Guardians. The initial concept was to create a semi-autonomous state agency with funding appropriated directly by the legislature but channeled through the State's Department of Health and Human Services.

It should be noted that the decision to create a public guardian agency was met with considerable controversy. Advocates for the elderly and persons with disabilities were concerned about the impact of guardianship on the liberty of their clients, state government officials saw the office as a potential additional drain on fiscal resources and judges of probate were concerned about the qualifications of the individuals employed by the office they would be asked to appoint when there was no other available alternative. In response to these and other concerns, the groundwork for the Office of Public Guardian was laid.

Initially, a determination was made that the Office of Public Guardian needed to be free to act independently on behalf of its wards. An internal structure was created to guard against actual or perceived conflicts of interest. An opinion from the Office of the Attorney General was issued which stated the Office of Public guardian was a fiduciary and as such it was an independent state office and was not programmatically under the jurisdiction of the Department of Health and Human Services or any other state office or agency and that accountability of the Office for actions taken on behalf of its wards was solely to the probate court. It was also decided that the Office of Public Guardian would not act as petitioner in guardianship cases or in any way be involved in cases prior to actual appointment as guardian. Examples of other initial policy decisions to insure independence and quality of services include caps on caseloads, a bar against locating offices on the grounds of state institutions and the development and adoption of a code of ethics which required the guardian to follow the dictates of the doctrine of substitute judgment in making decisions on behalf of wards. In short, an overall philosophy was developed which was in accord with the idea that, as a fiduciary, the public guardian was in the same position as any other guardian and was bound to exercise the highest degree of honesty, fidelity and loyalty in activities in relation to its wards.

III. Current Status

Despite the above efforts the employees of the state Office of Public Guardian remained in a position of perceived conflict of interest. Other models for providing guardianship services were reviewed and a decision was made to develop legislation which would abolish the Office of Public Guardian as a state agency and instead allow the state to contract for the provision of guardianship services. This statute, NH RSA 547-B, became law in 1982 and contains the following salient features:

- (a.) The state is required to contract for the provision of guardianship services with non-profit corporations which are approved by the New Hampshire Supreme Court;
- (b.) The contract may include the provision of other services which are protective in nature such as conservatorship and power of attorney services;
- (c.) The contractor shall not provide direct services to individuals being served under the state contract. Direct services are defined as clinical, housing, treatment or other services already available to the client;
- (d.) The contractor is not prevented from providing guardianship and protective services to other parties outside the scope of the contract; and,
- (e.) The contractor is required to maintain the "highest ethical standards" in providing guardianship and other services under the contract.

In 1982 the newly formed Office of Public Guardian, Inc. obtained the necessary approval of the New Hampshire Supreme Court and entered into a contract with the State of New Hampshire to provide guardianship services. The initial contract was with the Division of Mental Health & Developmental Services and was a "fee for service" agreement. Incorporated into the contract was language recognizing the Office of Public Guardian as a fiduciary and requiring the State to refrain from interference with all activities undertaken by the Office on behalf of its wards. Similar language has been included in all subsequent contracts with state agencies. The Office of Public Guardian also began to provide services to non-indigent individuals in situations where friends or relatives were not available or qualified to serve as guardian. The estates of these individuals were charged for the cost of guardianship services on a sliding scale basis subject to the approval of the probate court.

Currently the Office of Public Guardian provides services to approximately 600 individuals (approximately 20% of these people are not indigent) and has an annual operating budget of \$750,000. Staff includes an executive and deputy director, 10 guardians, 3 estate managers and 3 clerical workers. The caseload is divided equally between elderly and mentally ill persons and people with developmental impairments.

IV. Principles and Guidelines for the Provision of Public

Guardianship Services

Until the relatively recent advent of the National Guardianship Association most guardianship programs developed in a vacuum. With few exceptions, what little literature there was available tended to be highly critical of the very idea of public guardianship and was not empirically based. In New Hampshire the approach developed to providing guardianship services has been based upon a number of discernible principles and guidelines. An outline of these principles and guidelines follows.

A.) Public guardians should take a leadership role in providing professional, high quality fiduciary services.

While a pre-condition to the appointment of a public guardian should continue to be, among other things, the lack of a friend or relative available and qualified to serve, this should not imply that public guardians should not be highly trained, professional decision makers and advocates. Public guardians should be a community resource for family members, lawyers, courts and others involved in the guardianship process. Providing training and education should be an important function of a public guardianship office. Public guardianship staff should have a high level of expertise in a variety of areas including withdrawing and withholding treatment, financial management and public benefits, housing, community treatment alternatives, ethics and advocacy. In addition public guardians need to be especially familiar with legal procedures for terminating and limiting guardianship.

B.) Public guardianship offices should have in place ethics and standards for decision making and should make a practice of using these in day to day decisions on behalf of wards.

While codes of ethics and standards are a relatively recent phenomenon in this area their importance cannot be underestimated. In addition to providing decision making and programmatic guidelines for public guardians the existence of an ethical code and standards allows for increased accountability of public guardians as well as a higher level of predictability and consistency in decision making.

C.) Public guardianship services should be provided by court approved not-for-profit corporations which should provide a variety of guardianship and other surrogate services.

The not for profit corporation is the best available entity for providing guardianship and other surrogate services. Such organizations must however have the prior approval of the state judiciary as condition of doing business. This approval will help ensure that only qualified, fiscally sound organizations are appointed and that state contracts are not given to the lowest bidder or the most compliant guardianship agency.

Once approved the corporation can then proceed with entering into contractual agreements with state agencies or other organizations for the provision of guardianship services. These contracts should be fee for service agreements and should in all cases include clauses recognizing that the guardian is a fiduciary and, as such, must be free to make independent decisions on behalf of its wards and clients.

D.) Public guardians should provide services to all appropriate individuals regardless of income.

The public guardian should not be limited to providing services to indigent clients. Fees for its services may be on a sliding scale basis and should be subject to the approval of the probate court in accordance with state law. By entering into the market place the public guardian office will be in competition with the private bar, banks and trust companies and other providers of fiduciary services. This competition will help ensure that the public guardian office provides high quality, professional services. It will heighten the status of the public guardian and will add to the fiscal stability of the office. The ability to generate fees should also be seen as a way of increasing the quality of services provided to indigent people.

E.) Public guardianship offices should provide a broad array of surrogate services but should be statutorily prohibited from providing clinical or other direct services to individuals.

The expertise developed by guardianship agencies can be useful in the provision of money management, attorney in fact, guardian ad litem and other similar services. As previously noted it is absolutely necessary for the guardian to remain free from conflict of interest. Given the legal dictum that a guardian stands in the shoes of the ward and as such is a consumer of services on the ward's behalf, it is of fundamental importance for the public

guardianship agency to be free standing and not be in any way connected with agencies that provide clinical, housing, or rehabilitative services to its wards. Furthermore, the public guardianship agency itself should scrupulously avoid providing such services to its wards.

F.) Public guardianship offices should maintain a low public profile and should always encourage the use of less restrictive forms of interventions.

Too often public guardianship has been viewed as a panacea for the resolution of difficult social problems. While there are many instances in which the appointment of a legal guardian is necessary, public guardianship agencies should take steps to ensure that all alternatives to guardianship have been thoroughly investigated prior to its accepting appointment. While guardianship statutes often require the use of such alternatives it is often necessary for the public guardian to provide education and training to state agencies, nursing homes, and other providers, including both bar and bench, on these alternatives. The public guardian should also seek to terminate or limit the guardianship whenever possible.

V. Conclusion

The obligation to provide guardianship and other protective services can be expected to continue well into the future. This obligation will of necessity involve some form of public guardianship. Public guardianship agencies are vested with enormous responsibilities. The need to provide ethically sound, professional fiduciary services in a fiscally responsible manner presents a very complex problem. This statement is an attempt to provide some experience-based guidelines and principles for the provision of public guardianship services in jurisdictions throughout the nation.

Ms. KINDERMANN. Thank you.

Our next speaker is Penny Hommel, the Executive Director of the Center for Social Gerontology in Ann Arbor, Michigan. She's been active in gerontology for years as one of the first gerontologists to specialize in the legal rights of older persons. In 1976, working jointly with the law school, she developed and directed one of the earliest university based law and aging programs in this country, at the University of Michigan's Institute of Gerontology.

As a consultant to the Michigan Office of Services to the Aging in the mid-1980's, she focused upon issues of abuse and neglect in guardianship and served as liaison to the Commission on Long-Term Care. She became Director for the Center for Social Gerontology in 1985 and has since guided its position into the National Support Center on Law and Aging.

She writes for and edits the Center's two newsletters as well as numerous articles for practice manuals. She conducts training across the country on delivery of legal services, and substitute legal issues affecting older persons. She has special expertise and interest in the area of elder abuse and neglect, guardianship and alternatives, and is currently directing a groundbreaking national research project to look at how guardianship is imposed and what needs or problems trigger petitions for guardianship. As a result of her interest in surrogate decisionmaking, she has become increasingly involved in the issue of autonomy, medical decisionmaking, and the importance of advance directives. She has written and spoken extensively on this topic.

Penny.

PENELOPE A. HOMMEL, EXECUTIVE DIRECTOR, CENTER FOR SOCIAL GERONTOLOGY, ANN ARBOR, MI

Ms. HOMMEL. Thank you, Anna.

I am delighted to be here, and commend the committee for organizing these very important gatherings.

The Center for Social Gerontology has worked on the area of guardianship for many, many years and looked at it in different ways, from developing standards for providers of guardianship services to looking at the need for legislative reform, doing some major research around the country.

But what I want to talk about today is what to me is the most exciting of the things we've been involved in thus far with respect to guardianship. And that is a demonstration guardianship mediation program that the Center has undertaken and has now actually completed a number of cases.

And just to give you a little bit of background on how we got this idea, it really came about 5 years ago, when the ABA Commission on Legal Problems of the Elderly was organizing its Wingspread Conference on Guardianship. And in order to set the agenda for that conference, what the ABA did was to circulate a questionnaire to people across the country, trying to get their thoughts about what were the most important issues that should be taken up at Wingspread. We took that questionnaire very seriously at the Center.

And it was for some reason, the timing was just right. It really prompted us to do some hard, hard thinking about what's needed

to be able to move forward in the area of guardianship. And what we realized is that many of their questions were around the things that we had been working so very hard on, the need for more due process rights, more procedural protections in the guardianship hearing process, the monitoring of guardians once they are in place.

And those are exactly the kinds of things we have been very interested in. And we sort of felt like we'd been spinning our wheels, and what is the best way to move forward to get the due process protections in place, and to really get those procedural protections in place. And so what we started to do was try and step back and say "Are we really asking the right questions?" I tend to be a very goal-oriented person.

So what I started asking myself is, "What are we really trying to achieve through this whole guardianship process?" As we tussled about that, what we thought, for us what we really were trying to achieve is to assess the needs of the alleged incapacitated person and really find out what they can do on their own, what they can't do, what they can do with some help, and really get a sense of are they—to what extent are they capable of functioning independently and maintaining their autonomy. So assessment seemed to us to be a real important part of what we needed to be looking at and thinking about.

We also thought it was important to look at the needs of the family members or the interested other parties that were filing the petition, that is, what was it that pushed them to file that petition, what were the needs that they thought were going to be fulfilled through guardianship and the guardianship process. Once we have that, then we thought what we really needed to look at was to find a mechanism for determining the least restrictive array of programs, services, and assistance that could meet the needs to the greatest extent possible of the alleged incapacitated person, as well as the families and friends involved in the guardianship petition, and to do that in a way that preserved autonomy to the maximum extent possible and deprived the older individual or the alleged incapacitated individual of basic rights to the least extent possible.

What we came up with is the idea of linking high quality assessment with mediation, that once we have the assessment and the information from that assessment, we want to be able to sit down with the interest parties, including the alleged incapacitated person, and see, based on the results of the assessment and the needs that that assessment had demonstrated, see if something could be worked out short of guardianship, or perhaps just using limited guardianship, or in Michigan it's also possible to get guardianship for just a single transaction, something like selling a house or doing a major financial transaction. So we wanted to see if we could sit people down together and work something out that really was minimizing the deprivation of right and autonomy and maximizing the potential that people had for independence.

Once we figured that out, we decided let's try and get some funds to do that. We immediately then thought of the negatives. And some of these were similar to negatives that people have come up with in talking about the possibility of mediation in abuse and neglect cases. And the biggest potential negative that we saw was the

imbalance of power, that the alleged incapacitated person really may not be able to participate meaningfully in a mediation process. And so what we tried to do to minimize that problem was to first of all always have the court appointed guardian ad litem involved in the mediation process, and in Michigan there is a GAL appointed in every case.

We also recognized that it was absolutely crucial, and this is why initially our own staff attorneys are doing all the mediation, we realized that it was crucial that the mediators be very, very sensitive to the imbalance of power issue, and to recognize when the person really is not understanding or is incapable of understanding the mediation process and participating meaningfully in it, and then only handle cases where it really is appropriate.

So we do not mediate in cases where it seems the alleged incapacitated person isn't capable of understanding and participating. We also don't mediate in cases where there is any kind of allegation of abuse or neglect. We just say that's not an appropriate case.

The way it works, and we've been extremely fortunate in Washenaw County to have a probate judge who is very concerned with guardianship issues and always looking for ways and wanting to work with us in trying to find ways to improve the guardianship system so that it works better for people. So we set up a system with the court whereby they, when somebody petitions, will give people a brochure that we have prepared and that describes what mediation is, how it might help in their particular case, and the availability of our center to do the mediation. It's then totally voluntary, totally up to the individuals whether they call us or not.

I'll digress for a moment and say there have been a couple of terribly difficult cases that the judge has called us and said "Do you think you could help, if I can convince these people to work with you?" But by and large it's totally voluntary, and people choose to try it or not to try it.

What happens then is the petitioner or sometimes the potential ward calls the Center. One of the most time-consuming things we have discovered is then actually setting up the mediation. Because we try to involve all the relevant parties. And most of the cases that we have had have involved very large families. So it's trying to get people after work hours, trying to get the guardian ad litem in those after work hours, and get everybody together at the same time. And that often has taken many hours, it seems, just to set it up.

During the call, we do an initial interview to try and screen out inappropriate cases, and to make sure that it really is right for mediation. And then we set up the mediation, we also then set up with our Turner Geriatric Clinic, which is part of the University of Michigan, an assessment. And when I talk about replication in a minute, I'll tell you, to my mind, one of the biggest gaps in the guardianship area is the availability of people who really understand and know how to go about doing a good, high quality assessment.

We then, at the appointed time, just sit down with all of the interested parties and begin to try and sort out what are the needs, what are the issues, and how can the issues and problems be addressed, and how can the needs be met. We have used, as I said,

two of our staff attorneys, so that they are trained not only in mediation skills, but are very attuned to the issues around guardianship and to things like the imbalance of power.

What we have found is we usually are not able to resolve things in the first setting. Usually what we get into, given the kinds of cases we take, and these for the courts are the most problematic cases, I believe, given the kinds of cases we take, what we're really dealing with are very longstanding family disputes where for years and years and years there have been struggles within the family.

And in almost every case that we've had, the competence of the older individual is almost a side issue, that what's really being mediated are these longstanding family disputes, because what's really going on is a struggle usually among children about who gets control over mother or father, and who makes the decision about where they're going to live and how they're going to spend their money. And so with those kinds of cases, mediation really does seem to be a very, very good response.

What we have found is after many long hours, usually, and many heated, heated discussions, where the families really begin to confront, usually for the first time, these disputes and very strong feelings that have been under the surface for many, many years, we have been able, in the vast majority of the cases, to come to an agreement where we get an array of services in place and assistance in place, and then the petitioners have withdrawn the petition.

What we hope to do, if we've got some money, is to go back about a year later and see then what's happening, whether they are right back in court and battling each other again, or whether just getting the services and assistance in place is enough, and the mediation has done enough to teach the families how to handle their own disputes in a more constructive way rather than trying to do it through this destructive way of petitioning for guardianship.

In terms of replication, I think overall, if people are very sensitive to the kinds of cases that are appropriate, I think mediation can be a very valuable thing, simply because of what I just said, that usually what's at issue are these family disputes that are longstanding and very deeply felt. Good mediation can be extremely effective in those cases.

The biggest problem, I think, in replication is that what we've done has been very expensive. All the setup has taken a great deal of time. The fact that we have not set a limit on the amount of time we're going to spend with a family has meant that it can often be 8 hours of back and forth doing the actual mediation. So the cost is very, very high.

What we are recommending, because there is a lot of interest in other parts of the country in trying to do this, is that if you are going to try and do it, you work through some kind of existing community dispute resolution center. And also to the extent possible, and to the extent that you can set up training that you try and use volunteer mediators, if they really are very well trained and sensitive to the important issues.

A couple of other big problems, one I've already alluded to, is getting a high quality assessment. Even our Turner Geriatric Clinic simply has not had a real understanding, and I'm not sure that any

of us have a real understanding, of what a high quality assessment for purposes of guardianship, really means.

But also even more basic than that, I think people don't really think through assessment and think through how very, very important it is. Just as one example, when we were at the very beginning of the process, we wanted to observe, to the extent that it wasn't intrusive on peoples' privacy. We wanted to observe an assessment. It was an older couple that were at the clinic for a physical assessment as well as mental competency assessments.

And what happened, without any bad intentions, but simply because I think the Turner Clinic wasn't thinking through what it meant and how it might affect the older individuals being assessed, it was a couple, they were in, essentially, an examining room in the medical clinic, and they had been asked to undress, except for the hospital dressing gowns. So they were sitting there, waiting for the doctor to come in and do a physical exam while the person who was assessing for the mental competency was asking them questions.

And halfway through it, the doctor came in, and so the nurse said, "You'll have to leave", to the person asking the questions, and just totally interrupted it. They simply weren't aware that in that kind of unfamiliar setting, when you're not even fully clothed, that the risk of getting assessment results that cannot be relied on are very great. I think that one of the things we all need to be thinking about much, much more is just what is a good assessment and how to go about it and who can do it and all of those kinds of things.

The other big problem that we've found, as Betsy said early on, is that many communities simply don't have the array of alternative services that are needed by people. We have worked very hard to identify all the services that we can in Washenaw County. But there are still some big gaps. For example, we don't have a financial, a money management service in Washenaw County. So there is a real problem, and what we all need is a Cathedral Foundation and Terry to get that array of services in place.

With those caveats, though, we really do think, based on our experience, and as I say, it's very limited, short time, and small numbers of cases, we really do think that mediation offers a way to explore the real abilities and needs of the proposed ward and to work out family conflicts while at the same time preserving autonomy and important family relationships to the maximum extent possible.

Ms. KINDERMANN. Thank you, Penny.

Our next speaker is Carol Jones, the Director of Guardianship, Inc., in Little Rock, Arkansas. She has her B.A. from Hendrix College in Conway, Arkansas and her Masters of Science in Social Work from the University of Tennessee. She has worked in the field of disabilities for 16 years, and has been Director of Guardianship, Inc., since its inception in November 1984.

CAROL JONES, DIRECTOR, GUARDIANSHIP, INC., NORTH LITTLE ROCK, AR

Ms. JONES. You left out part of what I wrote in my bio. I said I'm also a wife and a mother. I put that at the top, too, because what I'm going to be talking about is relationships. I thought it

was important for me to say, those are my two most important relationships.

Being the director of a guardianship program in Arkansas means that I spend a lot of time just talking to people about what guardianship is. Many people don't understand the concept of guardianship, they don't understand that it's not a panacea, that it's not something that will just fix everything for everybody.

Basically what we do is we recruit, train, and support volunteers who become limited guardians of the person for people who don't have family members available. We are funded by a Social Services Block Grant through Title XX, and it's administered through the Department of Human Services Director's Office. Our referrals come from Developmental Disability Services, Mental Health, and the Office on Aging Adult Protective Services. All our legal work is done through the Office of Chief Counsel of the Department of Human Services.

Our program came about because there were people in the Department of Human Services who looked around for a way to get limited guardians for people who needed them. And I believe they looked at public guardianship as an alternative, but decided that we don't have enough money to do that. So they wanted to start a small nonprofit, to see if volunteers could be utilized as limited guardians.

They had talked to all the programs that you would think would be willing to start a program like this; they really thought it was an impossible idea. So they talked to the Arkansas Coalition for the Handicapped, which happened to be an organization run by volunteers, who thought this might be a pretty good idea.

We started absolutely from scratch, with no ideas, no contacts, didn't know what anyone else in another State was doing. Basically what they wanted to see first is if we could recruit volunteers and then if there was a way to support those volunteers.

We actually started with the Arkansas Coalition in 1984, and about a year and a half later decided it would be a good idea to separate from the Coalition and incorporated in 1986. That first year, we recruited four volunteers, developed our materials and spent time trying to figure out how to proceed. We now have 120 volunteers working in five different parts of the State.

Our staff consists of four volunteer recruiters who work in four different parts of the State. They are the people who go out and find the volunteers. The support persons are in Little Rock, and basically get as much paperwork done so that recruiters have time to go out and recruit volunteers.

When we first receive a referral, we go out and meet the proposed ward to see if it would be appropriate for us to be involved and to see if a limited guardianship will benefit this person. We investigate the situation.

Sometimes we run into community services that want a limited guardianship set up so that the person will do what they want them to do. For example, we had a situation not too long ago that a community service wanted a family to get a limited guardianship so that a woman would go into a sheltered workshop rather than go into community college.

In investigating, what we do first is we look for family. We try to see if there is any family involved at all or, if not, what happened to the family? We have been able to, and I really look back fondly on these situations, reunite some families. Because people have been away from their family for so long the family didn't realize they were needed. So we've been able to find people and put family back together. It feels really good to get people together, letting them meet their family again.

We also look for less restrictive alternatives. Again with the woman that they were looking at possibly potting in a sheltered workshop, what she said is "I want to go to the community college, and I want to get a job." For this woman that was a good alternative. We talked to the family and talked to the program about that being a more appropriate alternative than a limited guardianship for this young woman.

When we do recruit a volunteer, one of the things that we never forget, well, when we're doing guardianship at all, we don't ever forget that we are taking peoples' rights away. I think sometimes we get so hung up on talking about protection that we forget that people are losing rights as we do a limited guardianship. So we try to make sure that we don't ever forget that.

We also look at what decisionmaking means. Making bad decisions is not the same as not being able to make decisions. We find a lot, especially with younger people with disabilities, that families say "This person is making bad decisions here. And so we need a limited guardianship to keep her from dating this guy down the street." So we try to explain that to families, but a lot of times you get a real blank stare from them when talking about people's rights.

I think this kind of a program could be used with any group of people. I think anyone who needs a volunteer to help them get through the system could benefit from an advocate.

Volunteers can be used with children. We work with people over 18, but they can be used with teenagers. There are programs called Citizen Advocacy Programs around the country that do similar work. In fact, I have gone to several workshops to get as much of their material and take it home with me and see what we could do to really try to model after a Citizen Advocacy Program.

In order to replicate our approach, there are external and internal structures that are necessary. The external structures require a guardianship law that allows for limited guardianships. I don't know whether recruiting volunteers would be as easy if people had to be a full or plenary guardian. Also having independent funding is important.

Having Title XX funding through the Director's office at the Department of Human Services has been some protection for us. Because at least we're not right under the divisions that run services. So if someone in a division gets mad at you, you've still got the Director's office to go through. So we have had a little bit of protection there.

It's important to find funding that's independent, or protected somehow, so that when your volunteers go out there and do their job, which sometimes makes people mad, you're not going to have a lot of flak. You're not going to have someone coming after your

funding just because a volunteer went to talk to a provider of services about a situation.

Another thing I think that you must have is the ability to turn down inappropriate referrals. We have written that into our contract each year. I never want to get into a situation where we have to take referrals from the State. Because if we were in that situation now, we would be getting a guardian for the woman who would rather be going to college than going into a sheltered workshop.

You also have to have an understanding with everyone that it takes time to recruit volunteers. I can't say "Well, I'll have you a volunteer in 3 days." That's just not the way it works. Possibly we could have a volunteer in 3 days, but it may also be 3 months. It's just something that you have to factor in, that it does take time to recruit the volunteers.

The internal structures required include a certain philosophy. You have to believe that people have value and worth, that they deserve dignity and respect. You have to believe in the importance of human relationships. We talk a lot about relationships. I give whole workshops on relationships. Because for some reason we have forgotten how important they are in our lives. So we really have to understand how difficult it is for people to get help when they don't have connections to others who can help them speak out.

I think another thing you have to understand is that people are vulnerable. A lot of people don't understand how vulnerable people with disabilities can be. It's not always the gross abuse that you hear about, but it's just the neglect. We met a fellow that was considered profoundly mentally retarded, and he had a lot of funny head movements, everybody said "Well, he's profoundly mentally retarded, that's why he moves his head like that."

We got a volunteer who started spending time with him and she realized that he couldn't see. He was living in an institution and supposedly was getting all the medical care that he needed. The volunteer pushed for a sight evaluation, and they found that he had one detached retina and the other one was detaching. So no, he couldn't see well, he had to hold his head lots of different ways so that he could see at all.

The volunteer gave consent, because she was the limited guardian for medical care, for him to get the surgery that he needed. And now he can see.

Well, after that, of course, there was a battle as to whether or not he would wear glasses. And it took about a year to get him a pair of glasses, but that's another story.

One of the things that also takes a lot of time is training the recruiters.

People haven't done this kind of work before, so you really have to bring them in and teach them. And hopefully you find people who understand what we're talking about in terms of philosophy, who can really embrace it, maybe people who have seen abuse before or had to protect someone in their family. A lot of times those are the people who are best to go out and recruit volunteers.

As I mentioned before, recruitment takes time. One of the things that I've had to learn in working with recruiters is that they all have a different style and their own way of recruiting. I have a fel-

low that cruises around town looking for a particular type of person. He says, "I need a farmer, because this guy's real interested in farming." So he'll ride around town until he finds a farmer, and he talks to the farmer. He actually recruits that way.

We do targeted recruiting. When we have a referral of someone, we meet them and see what their interests are, see what their needs are and then we go out and try to find a volunteer that we can match with those needs. So for the fellow that's interested in farming, we found a farmer. It's not always that simple, but you do try to find people that would have something in common.

In retaining volunteers, one of the main things to do is to make sure the volunteer and the person have some similar interests. That's one way to help keep your volunteers.

You have got to be aware that volunteers are going to do it their way. So if you're faint of heart, you might be really careful about taking a job like this. We actually had a woman who got so tired of her ward being stuck in a State hospital that she locked a psychiatrist in his office and stood in front of the door until she got what she wanted.

We don't train people to do these kinds of things——

But it does happen. If someone's gotten overzealous, we might have to have a talk. But for the most part, they are going to do things their own way. So you may have some flak that comes back because of your volunteers, but that's okay.

Volunteers do need encouragement, particularly if they are dealing with services providers that are really difficult.

You do have harassment from time to time. When people are harassed and they are volunteers, they are going to need some support to get through it. So you have to be aware of that, and you have to be there for them when they need to talk to you. When difficult situations come up medically, you've got to be there for people. We have had some people go into comas, we have had people pass away and you do want to be there to support your volunteers during that time.

Our volunteers, the volunteers that we get, really get very little training. If you have not noticed already, we are moving away from our traditional program kind of setup. We're not looking at training our volunteers to be professionals. We talk to volunteers about treating the person that they are guardian for as if that person was a family member: Doing what you would do if this person was your brother, rather than Henry over here, and really sitting down and thinking things through.

That doesn't mean that we don't pull other resources in, and help volunteers talk to other people if they need that kind of thing. But we don't do a whole lot of training people to be friends to other people. We connect people, and most of the time, because we do our homework, it works.

We are recruiting volunteers to develop a relationship that's built on acceptance, no matter what the person's disability. In fact, we don't give a lot of details to volunteers when they first meet the person. We don't read that horrible record that they have had over the last 30 years in that facility to them. We do tell them if the individual could possibly be aggressive, of course, or if the person has a special medical need: Don't bring cookies if they're diabetic,

that kind of thing. We do fill them in. But what we've found is records of a lot of times do not really reflect the person.

We talk about emphasizing worth and potential and we talk about potential for everybody. We talk about potential for people with profound mental retardation, we talk about potential for people who are 88 years old. So we talk about things that can be accomplished for everybody.

We provide only as much protection and support as needed. You don't need to come in with a lot if all the person needs is someone to go out and spend time with them. Some people do need to learn social skills in the community, be reintroduced into the community. If that's really what the person needs, that's really what the volunteer needs to do.

Federal funding for volunteer programs would be a real good way to get more guardianship services needs met. I don't think we have to look at huge programs with lots of money. I think we can look at locally run programs. Our recruiters work out of their homes, so it's very inexpensive.

[The prepared statement of Ms. Jones follows:]

 Director
Guardianship, Inc.

Testimony Before

The
U.S. Senate Special Committee on Aging

"Innovative Approaches To Guardianship"

April 16, 1993

April 12, 1993

Ms. Anna Kindermann
U. S. Senate Special Committee on Aging
Dirksen Senate Office Building, Room G-31
Washington, D. C. 20510

Dear Ms. Kindermann,

One of the most critical aspects of our uniqueness as human beings is our ability to make choices--to determine what we wear, what food we eat, where we go, where we live and with whom we associate. These choices define who and what we are, they reflect our beliefs, preferences and dreams. Indeed, the choices that we make in our daily lives define our very personhood to ourselves and to society.

The dramatic importance of individual choice does not lose it's significance merely because mental or physical limitations are present. Choice remains a basic human right and a basic aspect of individuality. When our freedom to make important choices is limited, regardless of the reason, it diminishes our personhood. It diminishes self-respect and self-worth.

In reality, there are situations that seem to require that one person give up his/her decision-making ability to someone more able. If guardianship is used, it should be limited, tailored to the individual's areas of need.

The 1985 Arkansas Guardianship Act states:

"Guardianship for an incapacitated person shall be used only as necessary to promote and protect the well-being of the person, shall be designed to encourage the development of maximum self-reliance and independence of the person and shall be ordered only to the extent necessitated by the person's actual mental, physical and adaptive limitations" (A. C. A. 28-65-105)

With a state law that mandates promotion of maximum self-reliance and independence passed in 1983, a Limited Guardianship Project was started in 1984 as part of the Arkansas Coalition for the Handicapped. The program incorporated and became Guardianship, Inc. in 1986. Along with staff, a four member Board has developed a limited guardianship program that has recruited, trained, and supported 120 volunteers, 85 of whom are presently acting as limited guardians of the person. Some volunteers have been advocating for as long as seven years.

In developing this program, we found that recruiting volunteers to become limited guardians of the person requires both external and internal structures that are unique.

The first must in external structure (after a law that allows for limited guardianships), is a funding source for the program that is as independent of the service providers as possible. Our funding is a Title XX Social Services Block grant through the Department of Human Services. Because we report to the Director's office rather than one of the Division Directors, we have been able to weather times when some providers of services got tired of volunteers pointing out problems within their programs and wanted Guardianship, Inc. shut down.

Second, it is important for the program to be able to turn down inappropriately referred cases. This ability helps the program to avoid guardianships that are purely for the benefit of a program or an individual wanting to exert control over another person.

The third issue is getting the time to recruit volunteers. Recruitment does take time. This type of recruitment must be done through speaking engagements at various community organizations and through individual contact with interested persons.

There are internal requirements that are crucial to a successful program. The program staff and the Board made up of local community members must work from a philosophy that all persons have value and worth and should be treated with dignity and respect. There must be an understanding of the value of human relationships and the inclusion of all persons in the life of the community. Also an understanding that everyone wins when a vulnerable person is matched with a valued community member: the volunteer wins by gaining new experiences and maybe a new friend; the person with the disability wins because he/she has a personal relationship with someone who is not paid to be there, and the community wins when it can work towards inclusion and acceptance of people with differences.

All involved in the program must also understand that a guardianship should benefit the individual whose rights are being taken away. The guardian should be someone who knows the ward better than anyone else. And the guardian should spend time regularly looking at the appropriateness of services to assure that the individual is placed in the least restrictive environment possible.

The second internal requirement includes setting up the program so that the Volunteer Coordinators are trained to be able to take the internal structures or beliefs into the community. The Coordinators must understand the philosophy of the program so they will be able to recruit volunteers who can see the value and power of unpaid relationships in the protection of vulnerable people.

We have four Volunteer Coordinators in four different areas of the state who work out of the Little Rock office, donated office space or their own homes. Three support people run the central office in Little Rock to take care of as much of the paperwork as possible so that the Coordinators can spend most of their time on recruitment, training and support of volunteers.

In recruiting volunteer advocates, the Coordinator is doing more than just advertising for volunteers: he/she is involving the entire community by spreading information about the program and the philosophy to everyone who will listen. Recruited advocates are recruiters themselves; talking to people in the community about why they choose to advocate for another and encouraging others to do the same.

Once advocates have been recruited, there is also training and on-going support to take the Coordinator's time. We tailor training and support to each advocate's situation. Training can be as simple as an orientation to the living setting of the ward. Or if the situation is a more complicated one, a volunteer may need advocacy training and information on the services being provided or that need to be provided.

Support is simply what the volunteer needs. If a volunteer is dealing with a particularly difficult service provider, they might need a friendly "ear" on a fairly regular basis. Other volunteers who are comfortable with the services provided to their ward might not need support at all. We do produce an annual report on each guardianship and make sure it is filed with the court. All the volunteer has to do is add comments and sign it.

The program's aim is to recruit advocates who will develop a relationship with their ward that is built on an acceptance of the person, regardless of his/her disability; an emphasis on the worth and potential of the ward; a freedom from conflicts of interest; and a provision of only as much protection or support as needed.

Sincerely,



Carol Jefferies Jones
Director

Ms. KINDERMANN. Thank you.

I appreciate your pointing out that we're not just talking about older people. We are the Special Committee on Aging, but we're not just talking about guardianship issues for an aging population. We're talking about old and young.

Regarding Federal funding for volunteer programs, that's also something the Committee is exploring for an inter-generational program. So that may be something we will look at in the future.

Our last speaker, is Ingo Keilitz. He's currently the Vice President of the National Center for State Courts, and he's been there since 1978. He's a founding director of the Institute on Mental Disability and the Law, which is an arm of the National Center's research division. He's a lecturer in mental health law at the Marshall White School of Law, College of William and Mary. He's directed numerous national scope projects including the Involuntary Civil Commitment Project from 1981 through 1988. He conducts workshops and lectures extensively on topics related to the interactions of the justice and mental health system.

Dr. Keilitz has held both professorships in psychology at the Creighton University in Omaha, Nebraska, and in special education at the University of Missouri. Other positions include Director of Social Science Programs, Institute for Business Law and Social Research at Creighton University; Director of Research, Special School District, St. Louis County; Research Associate, Bureau of Child Research, University of Kansas; and a therapist with the Four County Kansas Mental Health Center.

He received his Ph.D. in experimental psychology from Kansas State University in 1971. He's the author of several monographs and books and over 50 book chapters, law reviews, and articles on topics on mental disability and the law, special education and psychology and program outreach.

Ingo.

INGO KEILITZ, VICE PRESIDENT, INSTITUTE FOR COURT MANAGEMENT, NATIONAL CENTER FOR STATE COURTS

Mr. KEILITZ. Thank you, and good morning.

I want to add my words of thanks to the Committee, and Committee staff, especially Anna Kindermann, for bringing us all together; I also commend the Committee for keeping this important topic on the national agenda.

Let me commend the audience. Part of my responsibility at the National Center for State Courts is for adult education. Your patience this morning and your attentiveness is very commendable. That's an informed commendation.

In the interest of time—we've been here a long time and I've got 15 minutes of material—what I would like to do, with your indulgence, is to make a little pact with you. If you will corral your attention for 5 minutes, I'm going to try to condense all my remarks into those 5 minutes.

I'm going to take a somewhat different tack than the rest of the panelists; it is suggested by the title of my prepared statement. I recommend the creation of an informational architecture for guardianship. The Federal Government should help the States accomplish this. I'm talking mostly about the State courts.

Without some kind of common language for the kinds of innovations that we're talking about this morning, we are not going to be understood. People will not be able to comprehend and appreciate the context in which these innovations were cooked up and place them into their own context.

And I can give many, many examples which I'm sure will ring true to you: "Oh no, I'm talking about uncontested guardianships." "Oh, do you mean children as well as adults?" "Oh, no, that's not what we call conservatorship in my State." "No, we don't have a probate court in our State; Our surrogate court handles that." "What is a surrogate?" "Our Orphans Court handles that." So the conversation proceeds.

Before we can take innovations developed in one State and adopt them in your State, there is a tremendous amount of time that has to be spent trying to understand what it is that was cooked up in Wisconsin or in Arkansas or in some other State. "What is this?" "How did they do that?" "We don't have a probate court in our State." "What is probate, anyway?"

What I'm recommending, and what the National Center for State Courts has begun to build, is a foundation, an informational infrastructure to support the sharing of information. This infrastructure has two important elements. The first is a national database for collecting the volume and composition of guardianship filings; the second is a set of descriptions of what all these guardianship systems really look like throughout the country.

In its 1987 report, the Associated Press lamented that there wasn't available even anything as basic as the number of guardianships filed in a particular State. And let me digress again, what's "filed" mean?

What's a case? It is reckless, and I think extremely frustrating, for us to talk about a particular kind of innovation and realize that we don't have the vaguest idea about how those innovations may translate to another context and whether those innovations are going to work elsewhere. It's a very risk proposition. Innovations and model programs are like old wine, they don't travel very well. The recommended infrastructure is the means whereby innovations can travel a little bit better.

If there is going to be reform in this area, we need to be able to answer questions such as: How many individuals are subject to guardianship proceedings annually in the United States? Do guardianship caseloads correlate with population? How do caseloads adjusted for population compare across different States and across the different administrative structures, across different guardianship systems? What social, economic, and legal factors contribute to those differences? Is it useful to know, for example, that one State may appoint 10 times as many guardians as another State with exactly the same legal structure? This is the kind of information that drives resources for the war on drugs, incarceration, and so forth. It's the kind of data that people in government use all the time. It's the kind of data that unfortunately we do not have in the guardianship area.

Based on some of our estimates, in 22 States, we projected that there are about 175,000 guardianships a year. The range of filings ranges from 18,870 in Michigan to a few hundred in several States.

If you look at the rate per 100,000 general population, it ranges from a low of about 9 or 10 to a high of 203 in Michigan.

These kinds of data can be extremely helpful in comparisons across States, and in moving resources to areas of improvement.

The second part of the infrastructure is some information on what the structural and organizational makeup of the guardianship systems is most of the guardianships are done in what we call probate courts, or probate divisions of other types of courts. What is a probate court? A probate court is what it is in my or your State. Probate jurisdiction varies across the country. All probate courts do decedents estates, wills, and trusts; not all of them do guardianships; those that do may not do guardianship of minors.

Again, the guardianship systems, implemented through the probate courts, are so varied that we don't know how to communicate with each other.

The point is that innovations are going to move a lot more rapidly across States, and be understood more readily, if we have informational infrastructure and a data base and a descriptive picture, a portrait, if you will, of guardianship systems.

Also needed is a set of national guidelines that provide a common language. These types of national guidelines can provide a philosophy of what optimum performance, optimum structures might look like. They provide a conceptual framework for understanding and improvement. They provide a common language. And most importantly, they provide a tool for management, reform, and self-improvement. These guidelines are not the type of standards that are imposed from above; these are not mandates. They are guidelines to help people talk to each other in the same language. The National Center for State Courts is involved in three standards development efforts described in my written remarks: the National Probate Court Standards, which should be done by the end of the year; the Trial Court Performance Standards; and, finally Guidelines for State Court Decisionmaking in Life Sustaining Medical Treatment. All form part of the envisioned information infrastructure.

Let me just mention one thing about the Trial Court Performance Standards. They were favorably mentioned in David Osborne and Ted Goebler's book, "Reinventing Government," which, as many of you know, is being used as a blueprint for reform by the Clinton Administration.

In short, what I'm encouraging the Federal Government to do, and all of you to do, is to help build this information infrastructure for guardianship so these innovations that we're talking about can be more readily moved from one jurisdiction to another.

Thank you.

[The prepared statement of Mr. Keilitz follows:]

**The Federal Government Should Help The State Courts Build
An Information Infrastructure To Support The
Transfer Of New Knowledge About Guardianship**

**Written Statement by
Ingo Keilitz***

* Vice President, National Center for State Courts, 300 Newport Avenue, Williamsburg, Virginia, 23187-8798.

"It is one of the happy incidents of the federal system," wrote Justice Louis D. Brandeis over sixty years ago, "that a single courageous State may, if its citizens choose, serve as a laboratory; and may try novel social and economic experiments without risk to the rest of the country without such information." As was made plain in the first in the series of workshops on guardianship, "Roundtable Discussion on Guardianship," sponsored by the U.S. Senate Special Committee on Aging in June 1992, there are more than a few courageous States willing to develop and try novel ways to improve their ailing guardianship systems. An important way that the Federal Government can contribute to reform of guardianship is to build the States' capacities for generating, disseminating and using new knowledge and innovations.

Innovations and model programs are like old wine, they do not travel well. Officials in Poughkeepsie, New York, may be reluctant to adopt the innovative guardianship monitoring system developed in Phoenix, Arizona, and for good reasons. Quite simply, although they may be eager to implement innovations successfully tried elsewhere, they may be unable to translate the innovations to their own needs, conditions, and unique guardianship system, and unwilling to take the risks of putting in place programs and procedures not designed for a system like theirs. The Federal Government can help minimize these risks by encouraging the development of an information infrastructure whereby the States can analyze the innovations tried elsewhere, compare the structures and conditions in which they were developed to their own, and more easily transfer the innovations. Such an information infrastructure has two important elements: a national database and a set of guidelines or standards for improvements.

A National Guardianship Database: Caseloads, Structure and Organization

A national guardianship database—including the volume and composition of guardianship cases, and the structure and organization of guardianship "systems"—is needed to describe, understand and analyze innovative policies, programs and procedures aimed at improving guardianship and to evaluate whether they should be disseminated beyond the borders within which they were developed. It is risky, even reckless, to promote innovations to cure an ailing guardianship system if there is no way of knowing if the innovations will achieve their goals or simply create more complexity.

Volume and Composition of Guardianship Cases. In its 1987 report of a nationwide study of guardianship, the Associated Press stated that there were no statewide records of something as basic as the number of individuals in a state subject to guardianship proceedings. It is difficult to imagine how it will ever be possible to develop—except in a very slow and piecemeal fashion—informed policies and sensible programs to cure the ailing guardianship systems throughout the country without such information. How many individuals are subject to guardianship proceedings annually in the United States? Do guardianship caseloads correlate with population? How do caseload levels, adjusted for population, compare across different states, jurisdictions and administrative structures (i.e., guardianship "systems")? What social, economic, legal and systemic factors affect the rates of guardianship filings? Is it useful to know, for example, that one State appoints ten times as many guardianships per 100,000 population than its neighboring State?

Neither the justice system nor the social service system--both of which have long-standing programs for the development and reporting of "case" statistics--possess a meaningful portrait of the volume and composition of guardianship cases throughout the country. Such a portrait is critical to the generation, dissemination and sensible use of new knowledge. The pragmatic justification for caseload statistics on guardianships is compelling. Caseload statistics are the single best way to describe what States are doing currently and to predict what they are likely to face in the future. Skillfully developed caseload statistics are powerful evidence for justifying claims made for innovations and for needed resources. An examination for caseload trends over time offers an historical perspective. It provides information about whether caseload growth or decline is consistent among States and across types of guardianship cases.

The level of public debate, policy and action on various social issues tends to wax and wane dramatically as the Nation's media highlight particularly heinous or unfortunate cases. Proposals for change often are based more on ideology and anecdote than on empirical facts. The absence of a national database on guardianship precludes answering critical broad-based questions about the scope of a problem, the nature of a problem and possible solutions. Systematic on-going data collection and evaluation are needed to understand the workings of guardianship systems, their shortcomings and the effectiveness of innovations and reform efforts.

The basis for the establishment and maintenance of a national database on guardianship already exists. Over the past 14 years, the Conference of State Court Administrators and the National Center for State Courts have jointly developed a model approach for reporting the volume and composition of state court caseload data and trends in litigation. The National Center's most recent annual report on caseload in the state courts--*State Court Caseload Statistics: Annual Report 1990*--for the first time includes the total state trial and appellate court caseload statistics from all 50 states and the District of Columbia and Puerto Rico. Although guardianship is a recommended caseload category, actual data collection is spotty. Some states (e.g., Connecticut) and some courts (the Maricopa County Superior Court in Arizona) do report guardianship data, but most jurisdictions do not. Because of the diversity of the state guardianship systems, the data that are collected are often difficult to interpret and virtually impossible to compare across the jurisdiction.

However, accurate and reliable caseload data on the nature and use of guardianship throughout the country can be successfully established. A rudimentary mechanism already exists as part of the Conference of State Court Administrators' and the National Center for State Courts' model approach for reporting the volume and composition of state court caseload data. Widespread expressions of need and the importance of caseload data in an area of such "special jurisdiction" as guardianship, and political will, are all that is needed to set the mechanism in motion. An adaptation of the existing model reporting system, which relies primarily on the cooperation of state court administrative offices, is a promising approach for the development and maintenance of a uniform database on the volume and composition of guardianship cases throughout the Nation.

Using the model approach for collecting and using state court caseload data, the National Center for State Courts' Institute on Mental Disability and the Law already has begun to compile a national database on guardianships. Based on preliminary data from 22 states and nine selected counties in 1990, the Institute was able to make tentative estimates of the total number of reported guardianship filings and corresponding rates per 100,000 population in the States. Based on the total number of guardianship filings in 22 states, the Institute estimates that a total of 174,565 guardianship cases were filed in the United States in 1990. The range of filings was wide from a low of a few hundred in several states to a high of 18,870 in Michigan. (If nothing else, these types of comparative data prompt inquiries about the social, economic, legal and systemic factors that may explain these differences between States. Michigan's relatively high rate of guardianship filings, for example, may be attributable to a regulation that was reportedly interpreted as requiring guardianships for all persons in nursing homes who do not have in place a valid, usable, power of attorney for health care.) Total guardianship filings per 100,000 population range from a low about nine filings in New York to 203 filings in Michigan in 1990. Guardianship cases appear to be highly concentrated in particular States. The five states with the largest guardianship caseloads--Florida, Georgia, Indiana, Michigan and Ohio--account for more than 63% of the total filings in 1990. All five are among the ten states with the largest populations, underscoring a relationship between population and filing rates.

Justice researchers, policy makers and administrators routinely rely on national statistics on crime rates, court cases and corrections populations to develop policies, to judge the adequacies of improvements and to respond appropriately to changing conditions. Similarly, a national database on guardianship is an important element of the information infrastructure for the generation, dissemination and use of innovative approaches to guardianships.

Structure and Organization of Guardianship Systems. A national database on guardianship should include descriptive information about the structure and organization of guardianship systems. As noted earlier, policymakers and administrators are unlikely to adopt innovations unless they have some assurance that the "laboratory" in which the innovations were developed is sufficiently similar to their own to warrant adoption. The adoption of innovations at the local and State levels depends on an accurate picture of the structure and organization of the system in which those innovations were developed.

As part of several on-going efforts, since relatively little is known about the structure and organization of probate courts--the major governmental entity responsible for guardianships--the National Center for State Courts has prepared a tentative description of the structure, organization, and jurisdiction of probate courts and probate divisions of courts. Sound and comparable information about structure, organization and caseloads can help provide yardsticks against which courts and States can assess and improve their guardianship systems.

Nineteen states and the District of Columbia have limited jurisdiction courts or divisions of general jurisdiction courts that use the word "probate" as part of their official name. These states can be divided into three general categories: (1) 11 states with formal statewide probate courts; (2) 2 states and the District of Columbia with probate divisions or departments of general or special jurisdiction courts throughout that state; and (3) five states with mixed or different probate court structures and organizations depending on region of the state. Thirty-one states have no formal "probate" court structure *per se*, although some states may use a different name (e.g., "surrogate" in New York) to refer to the same court structure and in other states, courts may be organized according to general casetypes without structural or organizational elements associated with those casetypes. (For example, the Superior Court of Arizona in Maricopa County, in a state with no formal probate court structure, is organized into civil, criminal, domestic relations, and probate departments established by local rule.) Subject matter jurisdictions of probate courts and divisions throughout the nation varies considerably. Only 15 of the 18 states and the District of Columbia with formal "probate" court organization, hear guardianship cases.

Standards and Guidelines for Improvement

Standards and guidelines for reform and improvement form the second element of an information infrastructure whereby the States can analyze the innovations tried elsewhere based upon a comparison of the structures and conditions in which those innovations were developed. Standards and guidelines are intended to provide a philosophy of what optimum performance, operations, and administration of guardianship entails; a conceptual framework for understanding and improvement; a common language to facilitate description, classification and communication; and, most importantly, a management and planning tool for self-assessment and self-improvement. The National Center for State Courts has been instrumental in developing and promoting three sets of standards and guidelines that are relevant to guardianship reform: the *National Probate Court Standards*, the *Trial Court Performance Standards*, and the *Guidelines for State Court Decisionmaking in Life-Sustaining Medical Treatment Cases*.

National Probate Court Standards. The need for reform and improvement of probate court administration, operations and performance has been expressed by groups and individuals both inside and outside of probate courts. National standards for the improvement of probate courts are viewed as a viable means to address this need. In 1991, the National College of Probate Judges, in cooperation with the National Center for State Courts, undertook a two-year project to develop, refine, and disseminate national standards for probate courts. Support for the project is provided by a grant from the State Justice Institute, with a supplemental grant from the American College of Trust and Estate Counselors. The central resource and mechanisms for the

development of the standards is the 15-member Commission on National Probate Court Standards, chaired by the Hon. Evans V. Brewster, former president of the National College of Probate Judges, and the Hon. Arthur J. Simpson, Jr., retired judge of the Superior Court of New Jersey, Appellate Division. The standards and associated commentary, annotations and reference materials are designed to bridge gaps of information, provide organization and direction to the future development of probate courts, and set forth aspirational goals that probate courts can work towards. They seek to capture the philosophy and spirit of an effective probate court.

The standards are divided into three major sections. Section I deals exclusively with performance standards (i.e., standards that probate courts can use to assess and to improve their performance) in five major areas of performance: (1) access to justice; (2) expedition and timeliness; (3) equality, fairness and integrity; (4) independence and accountability; and (5) public trust and confidence. (Except for alterations to make them applicable to probate courts, this section adopts all standards and commentary of the *Trial Court Performance Standards*, endorsed by the Conference of Chief Justices, Conference of State Court Administrators, and the National Association for Court Management (see below).) Section II includes standards for administrative policies and procedures for the probate courts including (1) jurisdiction and rulemaking, (2) caseload management, (3) judicial leadership, (4) information and technology, and (5) alternative dispute resolution. Finally, Section III covers probate court procedures, including (1) common practice and proceedings of the probate court, (2) decedent's estates, (3) conservatorship and guardianship.

Trial Court Performance Standards. Until very recently, court reform has focused on the structures and machinery of the courts, not their performance (what courts actually accomplish with the means at their disposal) and on the needs of judges and court personnel rather than directly on the needs of those served by the courts. No agreed-upon *performance* standards or criteria existed for trial courts of general jurisdiction. In August 1987, the National Center for State Courts and the Bureau of Justice Assistance of the U.S. Department of Justice initiated the Trial Court Performance Standards Project to develop measurable performance standards for the nations' general jurisdiction state trial courts. The standards are not rigid rules; they are guiding principles. By describing what trial courts should accomplish, the *Standards* shift the emphasis from *resources* (e.g., the number of judges, the availability of trained staff to support the efficient operation of courts) and *processes* (e.g., alternatives to formal dispute resolution, master versus individual calendaring, automated data processing, and one-day/one-trial jury services) to *performance* and its measurement. Although the *Standards* are designed for use by state general jurisdiction courts to assess and improve their performance, adaptation to special jurisdiction courts is possible and encouraged.

Guidelines for State Court Decision Making in Life-Sustaining Medical Treatment Cases. Developed by the Coordinating Council on Life-Sustaining Medical Treatment Decisionmaking by the Courts and the National Center for State Courts, under a grant from the State Justice Institute, these guidelines are divided into five sections: (1) issues that arise once a potential litigant knocks on the courtroom door but before a formal judicial trial is held; (2) issues related to the judicial hearing in life-sustaining medical treatment cases; (3) issues that may arise after the court has issued its determination; (4) issues uniquely applicable to cases involving minors; and (5) principles and policies that shape caseloads and caseloads in this area, with an aim for minimizing the need for formal court involvement. Although these guidelines do not focus on guardianship *per se*, they are a valuable resource for improvement of guardianship insofar as life-sustaining medical treatment cases often involve guardianships and the improvements suggested by the guidelines are, for the most part, applicable to guardianship cases.

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For more information about the National Center's projects described above please contact: the Institute on Mental Disability, the Law National Center for State Courts, 300 Newport Avenue, Williamsburg, Virginia, 23187-8798, (804) 253-2000.

Ms. KINDERMANN. Thank you, Ingo.

Before we begin the discussion, I should remind you for our court reporter's sake, please to announce your name, the organization you're with, and speak up. Also to the extent that anybody in addition to our panelists has statements or material they would like to submit for the record, you can direct them to my attention, at the committee address. I need them by the end of the month if you want them included in the record.

Why don't we begin.

**DOUG KAPLAN, YOLO COUNTY PUBLIC GUARDIAN
ADMINISTRATOR**

Mr. KAPLAN. I'm Doug Kaplan, I'm the Yolo County Public Guardian Administrator. Our last speaker, I agree with you, we have to have a common language. I run into that all the time.

What's your proposal on having a common language? How do we get there?

Mr. KEILITZ. It's always easy to point to what you're doing and assume that's the direction to go. The direction that we've been heading toward is the establishment of national guidelines. Again, it's very important to stress that these are not mandates, they are guiding principles for self-improvement. And they include this common language.

If nothing else, these guidelines allow us to order the world. For example, first, we have ordered the world into those things that happen before you ever knock on the courthouse door (e.g., the mediation programs that were mentioned). This may include things after you knock on the courthouse door but the court throws it back to you, as they do in many court-annexed mediation programs.

Second, there are those things, once you knock on the courthouse door but before you have a trial or hearing. Due process concerns appear here. Third, there are things that occur afterwards. What the standards do is focus things, then begin to get people to think along lines that are commonly understood.

So I think it's a very simple-minded conceptual approach to saying "Okay, let's order the world this way." There is room for people having different views of the world. We need more of that to bridge gaps.

SUSAN MILER, AARP

Ms. MILER. I'm Susan Miler, I'm on the staff of the American Association of Retired Persons.

I manage programs called money management, in which we have volunteers serving as representative payees and bill payers. And I also manage our national monitoring program regarding guardianships. For our money management programs, we have those programs located at about 70 sites around the country, serving 1,700 people. So I think we have substantial experience in trying to offer that service on a local basis as an alternative to guardianship. It's a way to prevent the exploitative kinds of abuse that can happen.

The thing I want to talk most about is the monitoring project, and I'm going to have Mary say a couple of things as well. Ingo's talking about all the different language. It's very real to us, be-

cause we're trying to operate in a number of courts around the country, all of which have different organizational structures, different kinds of languages.

I guess the message I'd like to say in particular is that courts should can monitor. In the aging series, that was one of the big holes that was pointed out, that they didn't have the capacity or resources to monitor guardianships. Over the past 4 years, I think we have found that they can do that, they we can train volunteers to help them out. We have looked at about 2,600 cases that our volunteers have researched for the courts, some of the things that we've found, and it was mostly that the courts simply couldn't locate the records and the guardianships were so old that in many cases they didn't know where the people were. So we created a whole set of volunteers to just do that, to try and find the people and the court records.

We have looked at now about 1,000 cases where volunteers have actually gone out and visited the guardianships to make sure that their care is adequate and that the guardianship is still needed. We have found cases that needed further intervention, we've found cases where the guardianship wasn't needed anymore, and having those volunteers out there to do the kinds of ongoing looking at the case that a couple of you have talked about. We also have volunteers who have served as auditors, who work with the courts and audit financial matters. In one court they have looked at over 2,000 of those recruited in the last several years, so it gives you some idea of the magnitude of work that just a handful of volunteers can do.

We've done most of this through several demonstration sites and two of those sites have shown that the volunteer program is very effective, even courts that were somewhat reluctant at first to really believe that volunteers could do this well have been won over, I think, and acknowledge the volunteers in much more complicated and difficult cases.

Based on the work that we've done on the sites, we have developed a handbook that's available for any court that requests it. It's a two-volume work, one volume which helps the court plan projects, and use the coordinator of the projects to do the day-to-day operation of it. The second volume is a trainer's manual, which is designed to help the trainer of the volunteers, and then the trainee's portion of that as well.

We see our main target as courts and judges, and are working extensively now to disseminate it and make it available to other courts. Mary Twomey, who's the other staff person, talk about that a little bit.

MARY TWOMEY, AARP

Ms. TWOMEY. Hi, I'm Mary Twomey, and I work for AARP.

I think I have one of the best jobs in the world, because I have the privilege of working with a cadre of volunteers across the country, who are some of the best people that any of you would ever want to meet. Anybody on the Federal or State level who ever wants to know, we really are inspired to work with these volunteers, particularly older volunteers, because they are working with people with disabilities, and they have a lot of sensitivity.

The other part of my job is to work with the courts, and what we're going to be doing this year, is to put the program into volunteers from five new courts. The individual courts that we are working with are the San Francisco Superior Court, in Kalamazoo, Michigan, and in Canton, Ohio.

For the first time this year, we are trying an experiment, where we will be working with the Office of Court Administration in the States of New Jersey and South Carolina to put the program into a couple of courts at once. The benefit of doing the program on the statewide model, using the staff at the Office of Court Administration, is that that the program exists in perpetuity in a court, it will put it into perpetuity at a State level, and reinstitutionalize it where their staff learns the training that we have put together, modify it for their State.

So in the future, if a court doesn't want to start the program this year, wants to start it in 3 years, they should be able to talk to their office support group. So that's going to be an interesting innovation for us.

Another interesting innovation for us is that in our current sites we are right now monitoring only the guardianships of adults. What I mean by that is that we're only monitoring someone usually statutorily over the age of 18 who has come under guardianship for whatever reason. So it's important that you know that just because we're AARP, we didn't come in and say "Oh, look, a young person under guardianship, we're not going to monitor it." Of course, that was never a question. We monitor all adult guardianships.

In San Francisco and Kalamazoo, we're just very concerned about knowing more about their guardianships of minors. They have no provision for monitoring the children in guardianship. Even in California, where they have professionals who are on staff of the court as monitors for the guardianships of adults, there are no similar staff for guardianships of children. So they are working with us to train volunteers to monitor guardianships of minors on those two sites. Also in Michigan, we have trained volunteers to monitor disabled guardianships and to adjudicate it in a different way.

Our hope is that other courts that are interested in the program, as we start to work with other courts in other States for next year, our hope is that as courts learn about the program and learn that it is very effective and very cost efficient, they will be contacting us so that we can take the program into more States. Someone asked me the other day, "Is it your hope that this program is in every State in the country?" Of course, yes, I said we hoped we could work with courts in whatever way is best for the court to monitor guardianships of children or adults.

DENNIS HAFFRON, ILLINOIS PROTECTIVE SERVICE COALITION

Mr. HAFFRON. My name's Dennis Haffron, I work for the Illinois Protective Service Coalition, part of the Illinois Alliance for Aging.

I've prepared a handout which some folks have gotten, I will follow the last speaker and again try and just make some comments on it instead of saying a lot of things. What we just wanted to let folks know is that we have been able to do things as a coalition.

And the basis of our coalition evolved through the fact that we decided not to focus in on the issue of guardianship or the issue of protective service but on the fact that what caused the need for guardianship was a disability, the disability being what we call decision impairment.

Doing that involved us with a whole bunch of other systems, and we started crossing over systems. We crossed over a lot of different social service and human services serving individuals with mental disability, disabilities such as developmental disabilities or mental illness, people with physical disabilities, and also people who have substance abuse problems, because that also causes decision impairment.

What we found was that by getting people to work together we found a much greater strength. We also found in our training programs that we could build local coalitions, and that the pieces were already out there, wondering why nobody else had ever talked to them. I think that's a sign. I was real happy to hear Carol's presentation on that, because I really think that there are some really good options available to us as we work through things.

And also, it broadens out the way we look at things. We came at this from the point of view of aging, from the Illinois Alliance for Aging. But it soon became very clear to us, to talk about decision impairment that's in any way related to aging was in itself ageist. And we had to, if we were going to deal with this problem, deal with it across all age populations.

So we found out the coalitions worked. We also focused in a little differently. We focused in on family members. We did guardian training with family members, because one of our coalition members, Mickey Iris, did some research on guardianship and said "Most of your guardians are family members or close friends who are already in existence. But nobody trained them in Illinois."

There was one guardian that we did in our training session, one guardian said "I was appointed guardian. I did everything, but I was told nothing." So what we thought to do was make the guardians that were in existence more effective as advocates. That also developed a constituency for guardian services for everyone. Because by reaching to those folks, those people became the constituents that supported not only the people that were their wards, but also understood the human factors and supported other folks with decision impairments. So the alliance began to build.

I just wanted to say those things. The other thing that our way of looking at things taught us was when the ADA came out, I went "Yippee! Here's something we can use." And then I found out that there was almost nothing in the Americans with Disabilities Act on the whole issue of mental disabilities at all. There's a big void in there. But it does occur to me that everyone involved in a guardianship process is covered by the Americans with Disabilities Act. Because one of the things is that you presume to have a disability.

Now, nobody should be in guardianship proceedings unless somebody presumed they had a disability. This may have some real impacts. One of the speakers mentioned public guardians as a right, the same way a public defender is a right. And it appears to me, one mechanism of that right, the Americans with Disabilities Act,

you know, how you tie it to Federal law, and this is a way you might be able to tie that to the Federal law.

Also just one more comment about language. We had a war, well not a war, a spirited discussion, at the ASA on the term, they have a workgroup on the ASA, a good group that's involved in working on seniors, disability and rehabilitation. Part of our coalition, the advocates for individuals with disabilities, got very upset about that. They say it isn't rehabilitation, for many of us is habilitation. And to say rehabilitation demeans some of us.

And that sort of language, apart from the fact that you're talking about legal, medical, and social in this issue. When you talk about language, it's not just the courts, different legal languages, you're talking about medical, social, and human services languages, all of which are tied in. So the needs are very strong to begin to tie people together.

We had one little thing where we managed to do it at a local level and if anybody wants more information, we'll give it to you. Thanks.

VICKI GOTTLICH, NATIONAL SENIOR CITIZENS LAW CENTER

Ms. GOTTLICH. I'm Vicki Gottlich, from the National Senior Citizens Law Center.

I have a question, and it actually stems from some of the inadequate statistics that I've seen, and how you would address it. Some of the studies I've read show that diversionary projects, or advance directives and pre-guardianship kinds of legal tools are used primarily by middle class individuals and by individuals who are white. And those of you who do guardianship diversion projects and recruit volunteers and whatever, I wanted to know what kind of recruitment you do to increase your availability to low income people and to people of color in your communities.

Ms. ABRAMSON. First of all, I agree with you 100 percent, Vicki, and I think that what you said is due in part to the fact that most of the planning on advance directives has grown out of the whole *Cruzan* case and the idea of "I don't want to be kept alive like a vegetable." People think about doing advance directives only for health care and they think about it only in terms of end-of-life decisions.

We have tried to put on training programs specifically targeted in the minority community. We do it with minority presenters on the panel and we do it in minority parts of the community. We find the reaction very different and justifiably so. Many minorities have spent a lifetime of having care denied to them. They are hardly going to fill out an advance directive saying "Keep giving me nothing." It's just not something that they are interested in doing, and is a totally different viewpoint than the white community.

I think that the whole use of the advance directive has to be rethought—what the purpose is for, to move toward the idea of it being a surrogate and advocate. No one should be supporting health care advance directives unless the documents are value neutral, not documents that are a "one size fits all" turn-it-off kind of document, but rather one that says "I'm appointing someone to speak for me whenever I am unable to," and to know that the advocate's there to make sure you're not still in your pajamas unshaven

at 2 o'clock in the afternoon in the nursing home, as well as those end of life kinds of decisions.

I think your point is also well taken in that I wouldn't call our work in getting people to fill out advance directives a guardianship diversion project. Because the people aren't on the brink. Terry is getting people who are almost at the door of guardianship and saying, "Wait, I can provide them services instead." To me that's where the real need is in the whole guardianship system. We can spend a lot of time tinkering with the guardianship system and the monitoring system and this and that, which is all very important.

But our data showed that the big issue is for people who are not even getting to the courthouse door, and getting in, and who are in need of services to prop them up and keep them in the community, and not thinking of "Oh, you can't make decisions, we've got to get you a guardian." That is not the end-all. Certainly low-income people have been shuttled out of the system disproportionately.

Ms. BARTON. May I address that question?

Because our program is almost 45 percent minority. We do serve low income and minority participants. And what she pointed out about the advance directives, the most important factor for many of our clients is to get an advance directive for health care. In Florida, we call them health care surrogates. And the intent of the health care surrogate is to make health care decisions, not the living will context, but to make that health care decision.

So much of the medical decisionmaking now requires informed consent, because there are so many varieties of procedures that can be done. And so the medical community absolutely demands informed consent. And that's where, with our low income minority population, it can be a very direct benefit, and so we advocate for that very strongly. And we have had a lot of success, I think, with our participants, in understanding the real need and getting their life in order.

But you're right, I think in terms of wills and trusts and things that are not meaningful in the context of their lives, but certainly health care decision planning, getting their finances in order, getting their finances organized. And they find this is advocacy, this is another thing that our program is very strong on. We have elderly people who were not getting SSI who were entitled to SSI, but simply by virtue of not knowing or not having been outreached to obtain it, did not get those benefits. So we do a lot, not only advance directives, but kind of trying to say, where can you benefit from the system that you may not be benefiting now.

JACK LOMBARD, AMERICAN BAR ASSOCIATION

Mr. LOMBARD. I'm Jack Lombard, representing the Property, Probate and Trust Law section of the American Bar Association, also the American College of Trust and Estate Council.

My question is directed to those of you who represent community based organizations. Will your organizations accept a designation as an agent under a durable power of attorney or a health care advance directive, the organization itself?

Ms. BARTON. We do accept that designation. Most of our powers of attorney are not durable. In some instances they may be. But

normally, as a corporate entity, everything that we do in terms of designation is as a corporate entity.

Mr. CASASANTO. The same is true in New Hampshire. We act as trustee, whatever.

Mr. LOMBARD. I'm surprised that your powers of attorney wouldn't be durable.

Ms. BARTON. Well, it depends very much on the situation of the client. It's client controlled. And if the client feels that that's what they want, we can do it. But we have a simple contract that basically says we're just going to do daily money management and it doesn't involve transacting for property or sale of property. That's the simplest arrangement that they can come in with, and many of our clients want that.

Ms. ABRAMSON. First, let's check the Ingo factor. Are we sure we're talking about the same thing when we say durable, Terry? So you're saying in your program, once a person—what do you case managers do when they come to you as a supervisor and say "Mrs. Jones really doesn't understand anybody any more." Does your power of attorney cease to be effective, and then what happens to those clients?

Ms. BARTON. Essentially in our program, if there is a question in terms of—there is no one else, by durable I understand what you mean is after capacity is gone. We will try to attempt a durable power of attorney for someone who may be diagnosed with Alzheimers, someone who obviously is going to diminish. But it is client controlled. And that's the thing that we try to keep. So we oftentimes start the regular power of attorney and it may advance to a durable power of attorney at some other point. We really take a slow approach in our clients lives. We don't go in with a sign-it-over-to-us attitude. It's how much intervention you really feel is necessary.

LARRY FROLICK, UNIVERSITY OF PITTSBURGH SCHOOL OF LAW

Mr. FROLICK. I'm Larry Frolick, of the University of Pittsburgh School of Law.

One of the things that strikes me about this discussion is what we will be thinking 10 or 20 years from now when we look back at these transcripts and see were we right, did we identify the problems or not. What strikes me is I would hate to look back and say how minor really the whole procedural issue, as Betsy inclined to say, are really going to look in the future. Because we are moving toward a world, it's very clear, of organized assistance for disabled and elderly. And whether that's because we have more people surviving with limited capacity or because the world is more complex, it's more difficult than it used to be to deal with this problem, or just the ongoing disruption and sundering of families so there is no one to provide a formal relationship.

We have more and more people needing this kind of assistance. I would think that Ingo is going to discover that more and more that the probate order in our State, the orphans court in his, is the proper mechanism for this. And I think it's rather odd to think that the same judges in most States who handle wills and trust and where guardianship is attached as a secondary function, it's not a

very good place to look for monitoring or a rather complex series of social services. The court was really designed to give a legal decision, do you need a guardian; and then to assign a guardian and hopefully, though they never did it, monitor it a little bit to see they did the right thing.

And as we move further beyond that, I think we're asking that, we're stressing out a system that will not handle it well. While I like the volunteer system, I think it's inappropriate to build a large army of volunteers from your judge by training this position. Rather we need, as in the New Hampshire situation, public guardians. They are not diversion projects, but where there are guardianship service providers, you are going to have to get social service agencies to contract money to pay service for hire foundations on the money. Then what you want to do is for the courts to be able to sign this little guardianship, after making decisions on the guardians, to sign the work out to some intervening agency, and then monitor organizations and advocates.

We should all be focusing on how we can help courts organize surroundings that will do this. I think if we continue to put the burden on these judges we are looking at people who are really swamped. They vary from State to State. But it's simply not going to be a solution to be coming into court.

Mr. KEILITZ. I think that's absolutely right. And that's why I think we need national data to take a look at the big picture. There's something very interesting happening, and there's no data on this yet.

The courts are being thrust, both the appellate courts and the lower courts, into decisions about values, about moral and ethical matters that used to be taken care of by other institutions—the church, the family, the school. In a healthy society, the courts enforce values. Today, people are looking at the courts as a source of values. The courts are not designed to do this—it is new to them.

And even though judges are now in that position, and some of them are doing a wonderful job, it's really straining the system.

But I think Larry's right, we've got to watch out. He's optimistic, he thinks that we're all going to go back and read these proceedings 10 years from now. [Laughter.]

Ms. MILER. All I want to say is that I don't think you can look at the things that were said, in fact, what happens often, when you're going to monitor, the next stage is where's the supply of service to follow that, and where is that going to come from.

Ms. JACKSON. Mine follows very closely behind hers.

But I think that is an organization that is working on some of the very same issues. When we dealt with standards, we had to look at things like terminology. When we were looking at innovative programs, that's something we concentrate on, every conference that we have. I have cards I would be glad to give you about membership or more interest or if you're interested in conferences.

Mr. HAFFRON. Just a view of the thing, when you're talking about the whole issue of guardianship, I sometimes put it into a different context, which is, if we were talking about somebody with a mobility impairment, we might be talking here about the provision of services for say wheelchairs. When we talk about this whole

system, I think it's important to realize how broad a continuum we're dealing with.

And guardianship is only a small part of that continuum that focuses in on legal and it's only a very small part. Because really, that always appears to me, again, I'm not a lawyer. But it looks like you're talking about the choice between somebody's life and safety and their civil rights, or a big portion of their ability to make decisions for themselves. And it's a really hairy decision.

So I think there will always have to be courts involved with it, but I think there needs to be more assistance when they do it.

Mr. FROLICK. I'd like to bring up a couple of other things. The middle class version of guardianship is durable power of attorney. I was wondering, who's going to monitor these people? I suspect 20 years from now, we'll have an AP story about a scandal about some of these.

I don't have an answer at all. But I do think before we get to solving some problem, that maybe the word guardian has become a bad word, if you say guardian it's bad. But we're going to be using other words that would have the same association down the line. We know that, but we've got some obligation for thinking about what and how to solve that. It's going to be primarily a middle class problem, particularly with property management cases.

Ms. ABRAMSON. I would agree with that, Larry. And in our health care power of attorney, we do have such a provision under the "safeguards" section. We have a provision for court review, that any interested party may petition the court under the health care power of attorney, to review whether the agent is doing the right thing.

But I'm not as worried about agents under health care, as I'm worried on the financial side. In Wisconsin we have what I consider to be a bad statutory fill-in-the-blank financial power of attorney created by the uniform drafters of laws. One of our State Senators rushed it through our legislature last year and it is a terrible piece of legislation. One of the many missing pieces in it is any kind of safeguards. Certainly, we advise people that anyone giving a power of attorney should put in some third party monitoring. And I think the private bar can help in that, too, to put in some neutral third party.

But the problem is, they tell me, that when sitting with clients, they wouldn't be appointing their son if they thought their son was going to do this 8 years from now and be reported by the AP. Their son is perfect. Nevertheless, I think all laws—and certainly in uniform laws—there ought to be language that would encourage that kind of discussion. Because I certainly agree with you, there is significant abuse, including in their drafting. We have all seen people in advanced stages of Alzheimer's disease walking around with powers of attorney that were signed yesterday. And I just really doubt they had that capacity yesterday and their situation just plummeted that badly in a day or a week or whatever.

JOHN PICKERING, AMERICAN BAR ASSOCIATION

Mr. PICKERING. I'm John Pickering, Chair of the ABA Commission on Legal Problems of the Elderly.

The courts today don't have the resources and time to do the monitoring. If we build into these alternative activities a constant source of review or a possibility of going to court, that's just kidding ourselves. There are not the resources to do it, it defeats the purpose. It's one of the great problems, of course, and destroys the utility of this diversionary device, the durable power of attorney of the elderly. Many elderly people do not have someone that they can trust.

Now, these organizations, why should we trust it to be the repository, knowing that some public guardians, as was the case with the Bay State of Michigan, and as was pointed out during the Pepper hearings, the former public guardian was brought from the penitentiary to expiate his sins by confessing he had been appointed with no training. We simply cannot protect everybody. I would just raise a big flag of caution about writing review provisions into these durable powers. It's a big problem picking an agent in whom you have trust.

Family members can be faithful or they can be unfaithful. And you just simply destroy the utility of some devices by trying to be overly protective.

Mr. LOMBARD. Jack Lombard again. I would just echo what John has said. Because there is something that we all in this area lose sight of. And it's something that's said in the AP study. The AP study says that the system generally works well. Yes, there are abuses. There always will be abuses. I don't need a verbal power of attorney and I don't need to be a guardian if I have a bad motivation and want to take advantage of somebody. The courts are always there to take care of bad cases.

And John is also right, you don't build your procedures through bad cases. You build your system on the basis that most human beings have the right intention to take care of individuals, and thank God for it. If you make the system complex, if you're going to court every year, nobody is going to want to serve. I said this in my remarks at Wingspread years ago, I meant it then and I mean it today. Don't get your system so complex that the whole thing breaks down.

We're talking today about the problems we see, that there ought to be better ways of addressing the social services that are really needed for the people who have no family. That's what we should concentrate on, not building systems that are going to break down, that volunteer program that we have, the family members and the many volunteers that you represent.

Ms. HOMMEL. I was just going to mention one thing, and respond a little bit to the last two remarks.

I think that people may be taking more extreme views than we really intend. What I think is happening is for a long time, when there was such an overreaction to the horrors of guardianship and how the system didn't work, that durable powers of attorney and other alternatives were seen as a panacea.

And I think what we're now realizing is they aren't a panacea, and the thing that I was going to add to what Larry was suggesting is that in addition to building in and thinking ahead about some of the things that can go wrong in a durable power, one of the things that's always worried me is that people don't give

enough thought to what is it that triggers, who's going to decide the person really is incapable of continuing to manage their own affairs and based on what.

And I think what is being suggested is not to build a system that's so complex and has so many hurdles to jump over that people can't really use it, but rather to not look at the alternatives as panaceas and think very clearly about what they mean, where they can go wrong, and then build in enough into the documents and into the choice about who the agent is and all those kinds of things, to make it work as well as possible. But I do think the whole question of in a durable power, who determines when the person becomes incompetent and based on what is something that we haven't given enough thought to and really need to address.

DeCOSTA MASON, AARP

Mr. MASON. DeCosta Mason, with the American Association of Retired Persons.

I think one of the things that, a lot of time now is being focused on the guardianship system, and we've gone through a process where most States have looked at the laws, and attempted to come up with something that provides due process protection for individuals and so forth. We've sort of gone through this process of developing alternatives to guardianship. And now it seems that we are saying that we're giving people choices to make, but we want to protect people from those choices that they actually make. We're going to have people who are going to decide to do durable powers of attorney, but we want to make sure that even though they make those individual choices that we're going to protect them from those choices that they've made.

I think we have to not get into that debate. I think the best we can do is to give people the opportunity to decide which choice they want to make. You can make a choice and do a durable power of attorney, relying on the person they choose. No one should have a right, necessarily, to make a value judgment about that choice that you made or when you made that choice. We have to assume that you made the choice when you were capable of doing that, and that it is there to protect you if someone attempted to abuse you and had you do it at an inappropriate time.

I think the other thing we have to consider is, at least in the context of personal decisions and health care decisions that we have gone to the extreme where have now basically taken those decisions out of the court except for persons who don't have anyone that they can appoint or can be appointed to health care decisions and so forth. But we haven't done that with regard to financial decisionmaking.

And it's a question of whether society is at the point where it still holds property in a higher esteem than personal decisions. Because we still basically force people to make decisions either doing a durable power of attorney for financial management, or you have to go through a court process. Because the institutions that we have don't want to use any other mechanism for dealing with that.

I think that perhaps what we really need to be looking at, if we want to get the courts out of this process, is how you can get institutions to accept other mechanisms of dealing with financial deci-

sionmaking, or whether we are going to force it on people. I know the National Conference of Commissioners has come up with such things as the Uniform Custodial Trust Act, which could provide a mechanism for low-income people to become a part of this financial decisionmaking process without necessarily going through the court process.

I think you have to take the step back a little bit and look at the financial end of this and see if there are other mechanisms we can use that will allow people, especially low-income people, to access the system without going through the court process. Because I think what you're seeing more and more is that guardianship issues are becoming more issues for low-income people. Because people who have finances are able to go and have someone explain to them how they can avoid that process.

So the courts are now being stuck with issues of health care decisionmaking or personal decisionmaking for low-income people, and financial management for people who are low- or middle-income people. People who have finances, whether it has to do with their financial management of health care decisionmaking, who are middle income and upper income, are avoiding the system altogether, because there are alternatives out there for them.

So these protections that we're building in, if we're going to have public guardians and things of that nature, the things we have to look at are assurances that these public guardians are acting as advocates for these individuals as opposed to simply persons who are providing a service, giving them access to whatever services people think they're entitled to, as opposed to advocating for services that the individuals should be entitled to.

I think that we need to perhaps take the step back and not spend so much time on how we're going to mediate situations where guardianship petitions have been filed but rather to ensure that whatever systems we already have, because I think we've got systems in place now. The question is, how do we ensure that those systems are going to work, and protect those persons who within this society are least able to access these systems.

Mr. CASASANTO. I also think, DeCosta, that we have to look at the issue of choice with regard to the alternatives as well. We see powers of attorney just being given out to people, here, do you want to avoid guardianship? Sign this. Do you want to avoid having to get an attorney and going to court and spending the funds for your savings? Just sign this. And these things are being sold to people lock, stock and barrel.

And I think a lot of times informed choices aren't even really made when someone is sitting down and signing an advance directive or a power of attorney or whatever. And I think that's something that—again, I think once they're signed, I agree with what the other people were saying, I think we need to give people some freedom, and not protect them from their own choices. But I think the choice has to be an informed one as well, at the outset.

Ms. MILER. I don't think you can overestimate how difficult it is, too, to make that informed decision. It's like Carol said, people say "Guardianship? What's that?" All the clients we serve in our money management program are low-income people, and I can't tell you how many of them come in and say they already have a guardian,

and what they mean by that is someone who helps them with their life. But they have no concept of the formal system at all. They say they have a power of attorney, they don't have any paperwork, but that's just their perception of what their arrangement is.

Mr. CASASANTO. And we see nursing home administrators calling a family member, saying "The licensing people have been here, come down and do a durable power of attorney with your mother," and things of that sort.

Mr. HAFFRON. I think a couple of things ought to be said. Through the conversation I was making notes. One is, I think you ought to be concerned, not just people who don't have families, but the supporting family members that are also functioning as guardians. Because if they burn out, there's big trouble with the rest of the system.

The other thing is that a lot of these decisions about durable powers of attorney are made not because of the need or the financial considerations, and the people that are really hit are not just the poorest of the people who can often get free legal care, but they are the lower middle-income people who can't afford the money for these services and therefore are forced.

In Illinois, I had a lawyer who works in a rather high State position say when a person turns 18 who is developmentally disabled, at that point if they are presumed to be competent, have to sign a durable power of attorney and have the family take over. And have that person, then it's done. The civil rights may have fallen away here, but I know why they're doing it. Because these are families often that have taken care of their kids through their whole growing up period and want to continue to take care of their kids, and they can't afford the money to do it. That decision, that skews the whole system and that scares me.

ERICA WOOD, AMERICAN BAR ASSOCIATION

Ms. WOOD. I'm Erica Wood from the American Bar Association Commission on Legal Problems with the Elderly.

We provide technical assistance to States regarding guardianship and alternatives. And recently I've been working a lot with the State of Virginia. I wanted to report on a different kind of innovation taking place there. Take several steps back, where we're not looking to development of a guardianship program, but rather a means of evaluating the need for changes in that State. We're holding a series of 10 town meetings throughout the State, so that people can come, the public as well as lawyers and professionals, and talk about what their understanding of the needs of the systems are.

The first town meeting was yesterday way down in South Hill, Virginia, and I was there. There were 150 people attending. I think there may be considerable misunderstanding about what guardianship is. Some people were confused about the difference between guardianship versus powers of attorney. We also talked about abuse of powers of attorney. There was a lot of talk about monitoring, there was a lot of talk about the approachability of judges. Those were some of the things I heard at the first town meeting, and I think it will be interesting to hear what goes on at the next nine.

Ms. KINDERMANN. Do we have any other comments or questions?

Ms. ABRAMSON. I want to add to the discussion that given the concerns about court access and not flooding the court with these needs, and again in response to the *Cruzan* decision, I've noticed that a lot of States are developing family consent laws, and that hasn't come up yet.

We have talked about monitoring and no extra judicial anything, and that given that the guardianship system seems to be broke and not really helping people, this is why in part it seems easier to just essentially legislate into being what's going on anyway, of just letting family members make decisions. I am interested in other people's responses, or folks who come from other States, as to whether this is the way to go, to lessen the burden on the courts and just let families make these kinds of decisions.

Mr. CASASANTO. The problems with the family consent laws, really, as far as I tell, really involve the inability to find, to see where there are conflicts. And it kind of puts the hospital or the doctor in the position of making a determination that this is not the person, the statutorily described person has a financial interest or is just not doing the right thing. And it puts the doctor in that position.

However, a lot of the physicians are so frustrated with the guardianship process and durable powers of attorney, that they're more than happy to be in that position. So it is where things are going, and it's really just formalizing what goes on oftentimes anyway.

Mr. PICKERING. It's roughly the third level choice.

Mr. CASASANTO. That's correct.

Mr. PICKERING. The first is that the patient is able to make the choice themselves, second, we have urged the American Bar Association to have advance directives, and then in the absence of that, there are these family consent laws.

I think there are about 20 some States that have family consent laws. And this statute will allow a person to qualify a family member under the family consent law, which I think is a good provision.

Mr. LOMBARD. We in the section of Real Property, Probate and Trust Law and also the College, support the efforts of the National Commissioners. John has indicated that this proposed uniform law will be voted upon by the conference at their forthcoming meeting this summer, and I would suspect would be voted upon by the American Bar Association at the next mid-winter meeting in February of next year.

But I think that the important thing that I see in this legislation, and I do an awful lot of lecturing and working in the health care decisionmaking field, is that it's nothing more than a confirmation of reality. Because if you look at the number of cases in the health care area, it's less than 300. And if you go back to *Quinlan*, the last thing Chief Justice Hughes said in the *Quinlan* decision is that these are family decisions, they don't fall in the court. Which goes to the general premise that we don't have our courts and our courts can't solve every problem that exists in this area. We have to rely on the good faith of the people who act decently and fairly in all the areas.

Ms. HOMMEL. I just wanted to mention, that is exactly the push that we're seeing in Michigan. Because as Ingo said, because of

various overt provisions in this interpretation in Michigan, many of the judges have told me that the number of petitions they receive has at least doubled in the past couple of years. So there is a big push to get a family consent law.

And we have researched the family consent laws from around the country. The one that we were very impressed with, and I don't think it's been on the books long enough to really have a good sense of how it works, is the Colorado law. It really does think ahead as to, is this really going to get the most appropriate decisionmaker making the decisions. So it talks about not a single person in the hierarchy of decisionmakers, but rather a group of people, so that it would include, for example, a spouse and children. And it sets up a procedure for who has responsibility for notifying people around the country that they are part of this process. It then sets up a procedure for deciding who is kind of the lead person.

By what it does, and to me the most important thing that it does, is if there is conflict within this group of people that's supposed to be making the decisions, then it has the mechanism for trying to resolve the conflict and perhaps ultimately having to go to court if it really can't be resolved. But it recognizes that a simple hierarchy is not going to be the right decisionmaker for everyone. So it tries to incorporate a group and then take consideration of the fact that there may be conflict.

Mr. HAFFRON. In 1979, I was on the first group of people in Illinois to study abuse of senior citizens. And when we talked about surrogate decisionmaking, the presumption, which is fair in almost all cases, that people are going to make good decisions, I have to tell you that I have a certain amount of concern about the fact that people can abuse that, and understanding that that's going to happen, most of the cases, there still needs to be some protection in there, and it needs to be clearly spelled out. Because this could be another form of abuse.

We had one case where a guy had almost beaten his mother to death. And almost had the power of attorney, he would have had the power to determine whether to keep her on a machine and keep her alive. Now, the longer he kept her alive, then he's got a conflict of interest there. So those things, that's one thing I'm scared about.

Ms. KINDERMANN. Unfortunately, our time is up. Thank you very much for another very informative session. I don't know what the next workshop will focus on, but we welcome your input.

You will each receive a transcript of this forum. If anybody has any other materials they want inserted in the record, please let me know by the end of the month.

Thank you again for all your time.

[Whereupon, at 12:35 p.m., the workshop was adjourned.]

APPENDIX

GUARDIANSHIP TRAINING AND COALITION BUILDING

Report prepared for a United States Senate Special Committee on Aging workshop entitled "Innovative Approaches To Guardianship"

April 16, 1993

Dennis Haftron MS
Program Director
Illinois Protective Service Coalition

The Concept

This report will discuss how and why our coalition designed and implemented a training program for guardians in such a way that program acts as a basis for developing a coalition of agencies and individuals in a local area.

Why a Coalition?

The Illinois Protective Service Coalition is comprised of representatives of seventeen organizations and was established in 1988, as a special project of the Illinois Alliance for Aging. It was originally comprised of agencies that had been working together on various committees for up to eight years to identify needs and positively impact the delivery of services to persons in need of protective services, particularly the elderly.

Since 1988 the IPSC has evolved. The membership has broadened to include advocates and agencies serving all adults. The definition our actions has changed from advocating for the provision of services to advocating for individuals with a disability and for the family and social systems that support them.

This evolution was brought about by several shifts in perception. The first was that the focus of what we were dealing with was a disability rather than a group of services. We named this disability "decision impairment". The second was that to consider that decision impairment was age specific was ageist. The third shift was that by focusing on decision impairment as a disability we were able to broaden our base by linking with those individuals, groups and agencies who served individuals with disabilities. We also found that it was most efficient to confront this disability in all adult populations.

This change increased the need for coordination and the strengthening of possible cross system alliances. Our ability to confront this issue was enhanced by the fact that we were a coalition and as a group had knowledge and standing in various systems. We also felt that we could develop support from previously unlinked systems.

Our own activities and strength also predisposed us to the possibilities inherent in using coalitions for local training.

Why Guardianship?

One of the many areas in which we are working is the area of guardianship. In dealing with the issues surrounding guardianship in Illinois we faced several challenges 1) maintaining individual freedom and dignity, 2) lack of resources, 3) inappropriate application of resources, and 4) coordinating the many disciplines involved in this issue (i.e. medical, legal, human service systems, and individual family members).

Research and experience acquired by the Illinois Protective Service Coalition (IPSC) indicated that the most effective way to improve advocacy for those individuals with the most severe impairments was to train their guardians to be effective and responsive. With changes and cuts in programs which serve individuals with decision impairments and with the increasing complexity of service systems the need for effective guardians is critical. We believed that we could use our coalition contacts to have a positive effect in this area. Our original intent was to write a brief manual focused on the family member guardian and present programs with it through out the state.

Our intention was to begin a training program focusing on existing family member guardians for several reasons. Studies by Madelyn Iris indicated that family members were fifty one percent of guardians for adults in Illinois. Another four percent are friends. These volunteer guardians are appointed to protect over two thousand individuals annually. The results of a training program for volunteer guardians conducted in southern Illinois revealed how hard it was to recruit and maintain volunteer guardians. Also various coalition members had been receiving requests for help from guardians or encountered guardians who needed help.

We made contacts to conduct training and began to write a manual. This process involved a 7 individuals, most of whom had not been previously involved in our coalition. This concept, however, evolved.

The Plan

As a direct result of the experiences of the program conducted in southern Illinois and described to us by Howard Eisenberg we revised both our manual and, more importantly our presentation. The southern Illinois group found that the guardians they trained needed to understand their ward and the specific support systems the ward needed. Benefiting from this information we greatly enlarged our manual and involved and additional eight people several of whom were knowledgeable in various types of disabilities.

Southern Illinois project people also found that supporting volunteer guardian took almost as much time as being a guardian. Our concept became not to just give out the manual but to create a training group in each area. This group puts on the program and becomes a resource group for the local guardians. Our concept evolved toward building into the group members who already had the responsibility or inclination to assist guardians and individuals with decision impairment. We believed that such a group would stand a better chance of not burning out as a local resource.

We also have a step by step locally focused plan to present the program through out the rest of the state.

Step One: Recruit local contact agency, using contacts of members of our coalition

- Step Two: With the assistance of that agency, with the contacts from IPSC members, and with the contacts that we have with our training coalitions and the participants we will recruit local participants. Those participants will include a Judge, lawyers concerned with the populations served, human service agencies serving seniors and people with disabilities, advocacy groups, and individual guardians.
- Step Three: Conduct two to five meetings with the group to show them how to use the manual as a training aid, to help them to locate a place to hold the training, and to show them how to reach the guardians.
- Step Four: Maintain contacts, encourage and involve local groups and their members

Our immediate and intermediate goals are to continue and enlarge the guardian training effort in the state and use it to build and broaden the power of our coalition. We hope to:

- conduct and coordinate ongoing training programs in each jurisdiction,
- get courts to allow estates to buy training and manuals,
- get free manuals for guardians of indigent people,
- maintain a network of trainers and guardians,
- have the state require training for guardians and Guardians Ad Litem.

The coordination of the training programs and manuals and the pilot printing of the manuals has been provided through grants from the Chicago Community Trust, the Retirement Research Foundation and the Lawyers Trust Fund. The trainers, authors, and editorial committee members have all donated their time to this project. Additionally permission to use copywritten materials, use of facilities, use of equipment, and program refreshments have been donated free of charge. In Belleville the local mental health funding agency had the entire eight hour presentation taped.

Initial Evaluation.

The Illinois Protective Service Coalition has completed successful pilot training programs in Elgin and Rockford and Belleville. We have had thirty two individuals involved in conducting the training and 127 participants (35 in Elgin and 52 in Rockford and 40 in Belleville). Of the 60 from Rockford and Elgin who completed a pre-training questionnaire, 35 indicated that they were guardians and 15 indicated that they were considering becoming guardians. In Belleville 38 of the participants were guardians. As the result of our recruitment efforts of trainees we have the names of over 500 guardians of persons in parts of Illinois.

While the majority of the wards identified were young and middle aged adults more than one half of the guardians trained were themselves senior citizens. The wards were disabled as the result of physical and mental illnesses, developmental disabilities, and trauma. This information highlights the need for a multi-generational multi-causative factor alliance to provide the most effective support and advocacy.

As a result of our recruitment efforts of trainers many agencies have worked closely together who had only limited contact previously. Also very strong support from the courts developed. These links have not dissolved. We are linking these systems with our coalition in an attempt to improve the quality of guardianship and the strength of advocacy. We believe that this effort can be a model for other advocacy and multi-generational efforts.

We now have in place three regional training committees with the following membership:

The Elgin presenters include;
The Honorable Gene Nottolini, Kane County Chief Judge

Laurel Spahn, Esq., Staff Attorney, Office of the State Guardian, Elgin
 Steve Wendorf, MSW, Social Worker III, Elgin Mental Health Center
 Barbara Schiller RN, Assistant Director, Senior Services Associates, and a
 Substate Ombudsman

Janet Krahn, Association for Individual Development (A. I. D.)
 Deborah May, Director, Day Treatment/Vocational Program, A. I. D.
 Jane Lurquin, Coordinator of CILA Services, A. I. D.
 Emma Jean Christensen, Case Coordinator, A. I. D.
 Sherri Nocchi, Case Coordinator, Association for Individual Development
 Cathy Krikau, Director of Elgin Residential Services, A. I. D.
 Jean McGraw, Secretary, Case Coordination Unit, A. I. D., and a parent of a
 person with a developmental disability

This committee made its presentation at the Association for Individual Development, Elgin, on January 22 and 23, 1992

The Rockford presenters include:

Honorable Alford Penniman, Probate Judge, Winnebago County
 Attorney Sharon Rudy, Past President, Illinois Guardianship and Protective
 Service Association
 Dixie Hosto, Visiting Nurses Association of Rockford
 Barbara Clay, Secretary Rockford Alzheimer's Association and was a guardian for
 a person who had Alzheimer's Disease
 Melinda Trier, In Home Services Manager, Northwestern Illinois A A A
 Adrienne Langley, Administrator, Rockford Office of the State Guardian
 Steve Langley, Director, Stepping Stones
 Attorney Margaret Tyne, Staff Attorney, Rockford Office of the State Guardian
 Cathy Weightman-Moore, Catholic Social Services, Rockford, Substate Ombudsman
 Attorney Mary Gaziano, Winnebago County Public Guardian
 Jane Browning, Rockford Office of the State Guardian

This committee made its presentation at Stepping Stones, 706 North Main Street, Rockford, on March 3 and 10, 1992. Child Care and Refreshments were provided courtesy of Stepping Stones.

Metro East Developments

This area centered in Madison and St Clair counties and had two committees with overlapping membership. Their first program was held in Belleville on Feb. 27 1993. The attached letter indicates how this group, the first group not involved in writing and proofing our manual, is developing.

Comments from both the presenters and the participants indicated that this was a learning experience for all involved. Presenters indicated that legal and health service professionals as well as state ombudsmen could benefit from both the manual and a suitably adapted training program.

Trainees indicated that the first night in Elgin was "Too much material" and "Time spent on matters that did not pertain to the ward...". One participant suggested that "It would be better to divide the group to specific interests." This idea was tried, successfully, in Rockford.

Trainees comments included "This training is so needed and has been needed for a long time." and "Thank you for this necessary class." Several participants commented on the value of the training guide. One said "When I was appointed guardian I did everything..... I was told NOTHING."

The IPSC is currently negotiating with the Buehler Center On Aging to obtain an extended analysis of these training events and the individuals who participated in them. We have commitments for co-funding from the Buehler

Center on Aging and from the Illinois Guardianship and Protective Service Association.

The responses we currently have, from both presenters and trainees, already indicate that this is a needed program, that it can be well conducted by local people with only moderate support, and that it leaves a structure in place for further activities.

Members of the training teams in St Clair, Winnebago and Kane counties have indicated a willingness to hold regular training programs. The probate judge in Kane County (since elected chief circuit judge) asked us to use our manual and local committee members in a training of Guardians Ad Litem.

We are currently successfully utilizing the networks developed by our training committees for advocacy and in such areas as utilizing The Americans with Disability Act and defeating adverse legislation on Guardians Ad Litem.

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**IN THEIR BEST INTEREST:
The Guide for Illinois Guardians
and Other Surrogate Decision Makers**

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Editors:

Dennis Haffron MS, Christine DuSell MSW, and Sadelle Greenblatt Ph.D.

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A GUIDE TO THE GUIDE

Dear Guardian,

Thank you for assuming the responsibility of becoming a guardian. Everyone involved in developing In Their Best Interest realizes the importance of what you are doing as a guardian or surrogate decision-maker for an adult who is disabled.

The Illinois Protective Service Coalition was established in 1988, as a special project of the Metropolitan Chicago Coalition on Aging, now the Illinois Alliance for Aging. The project emerged out of earlier efforts to identify needs and positively impact the delivery of services to persons in need of protective services, primarily the elderly. Over the 3 years the scope of the coalition has expanded along with its membership. The current mission of the Illinois Protective Service Coalition is to build a comprehensive system of supportive, rehabilitative and protective services for adults of all ages who have decision-impairments and for their families.

Part of Illinois Protective Service Coalition's mission is to assist people who need guardianship or other surrogate decision-makers. Research indicates that the majority of guardians in Illinois are family members of disabled persons of various ages. These family members suffer from a lack of information and training about surrogate decision-making, relating to a person with a decision-impairment, guardianship services and community resources. In response, the coalition developed this guide and its accompanying training program.

This guide is intended to help you. There are several things that we want you to know:

The information in this guide will change as state resources change. As we receive new information we will be making changes. We ask you not to copy the text without permission. You may copy all of the forms.

You do not have to read all of this guide. We suggest that you use it as a reference book. Review the summaries. Read those parts that you think will help you in your role as a guardian.

Sections of this guide overlap. This guide is a collection of information. We have incorporated materials from all over Illinois and from Wisconsin and Michigan. We have left in the overlaps to preserve the structure of each section and to make each chapter easier to follow.

This guide has limits. This guide covers the entire state. It does not provide detailed information about each of the very different parts of the state. Check with agencies and people to find out what is happening here and now.

This guide is not a substitute for individual legal assistance. All persons who are involved in a situation that may require legal intervention are strongly encouraged to seek legal assistance.

Please refer to Chapter 3, Legal Aspects of Guardianship for Adults, for the definitions of legal terms used throughout this manual.

We hope that you find this guide useful. Please send your comments to:

In Their Best Interest
Illinois Alliance For Aging
327 South LaSalle Street, Suite 920
Chicago, Illinois 60604

PREFACE

The fact that the Illinois Protective Service Coalition is a joint effort of many concerned and committed individuals is amply illustrated by a work such as this guide. No one person or service system could have pulled together the diversity of resources and knowledge necessary to provide needed information for guardians serving in this state.

Additionally, the coordination of the creative energies of so many talented people itself required a team effort. Of particular importance where those professionals on the original guardian training committee:

Ellen Holden Clark, J.D.
Madelyn Iris, Ph.D.
Terrie Rymer, J.D.

Susan Gutterman, J.D.
Sharon Rudy, J.D.
Laurel Spahn, J.D.

These individuals provided inspiration, vigor, and a real world sense of what was needed in both a training program and a manual. At various times members of this committee, particularly Susan Gutterman, reviewed parts of this guide. Also critical were the participation of pilot training committees in Kane and Winnebago Counties. These groups field tested our manual by using it to train 37 guardians.

The committee members in Winnebago County were:

Honorable Alford Penniman, Probate Judge	
Sharon Rudy, J.D., Convener	Dixie Hosto
Barbara Clay	Melinda Trier
Adrienne Langley	Steve Langley
Margaret Tyne, J.D.	Cathy Weightman-Moore
Mary Gaziano, J.D.	Jane Browning

The committee members in Kane County were:

The Honorable Gene Nottolini, Probate Judge	
Laurel Spahn, J.D., Convener	Steve Wendorf, MSW
Barbara Schiller	Deborah May
Janet Krahn	Jane Lurquin, BS
Emma Jean Christensen, BS	Sherri Nocchi, BS
Jean McGraw	

The completion of this guide required constant data input, corrections, and organization that could not have been accomplished without the skill of the Illinois Alliance for Aging's support staff, particularly Carol O'Grady.

In recognizing the marvelous efforts of the above mentioned individuals, the editors acknowledge that in spite of the help they received and because of the fluid nature of the subject errors will have been made. The editors alone are responsible for any errors and would appreciate any feedback from the reader/user of this manual so that future editions can be improved.

STATE OF ILLINOIS

Jim Edgar
GovernorGUARDIANSHIP
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April 8, 1993

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Illinois Alliance for Aging
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Chicago, Illinois 60604

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Dear Mr. Haffron:

I am writing to update you on the positive outcomes from the Guardianship Training sponsored by the Illinois Alliance on Aging Illinois Protective Services Coalition. In a recent evaluation coffee 3/26/93 attended by the organizing committee members, the training seminar format and feedback was shared among the participants.

During the debriefing and ensuing discussion about the Madison county training (TBA) we discussed the need to broaden the focus of training and conduct a yearly regional training on guardianship. There is great commitment and perceived need by the organizing group to proceed in further training. This need has now been written into the budget proposal of Southwestern Area Agency on Aging. All organizing committee members readily agreed to continue participation and assist in the upcoming June 94 Regional Guardianship Training Seminar.

Additionally, growing from this networking process came the identified need to coordinate services across disabilities and ages. We have agreed to meet again to firm our interactive relationships and to include other service providers. This is truly an exciting opportunity for key players who perform services to identify needs and seek solutions to problems as our communications are strengthened.

Our group consists of the Southwestern Illinois Agency on Aging, Larry Miller, Exec Dir, Belleville Area College Programs and Services for Older Persons, Penny Neale, St. Clair County Public Administrator, Robert Stookey, Developmental Disability Services of St. Clair County Exec. Dir. Jane Nesbitt, St. Clair County Mental Health Board Exec. Dir, Dana Rosenzweig, Central Comprehensive Mental Health Center, East St. Louis, Vanessa Collier and our staff attorney, Dave West.

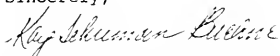
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Mr. Haffron
April 8, 1993

I am quite pleased our group has joined together in these efforts and will keep you apprised of our progress.

Sincerely,

A handwritten signature in cursive script, reading "Kay Schuman Buehne".

Kay Schuman Buehne, LCSW, ACSW
Guardianship Regional Administrator

KSB/lhv



THE ILLINOIS PROTECTIVE SERVICE COALITION

The mission of Illinois Protective Service Coalition is to build a comprehensive system of supportive, rehabilitative and protective services for adults who have decision-impairments and for their families.

Adults who have decision impairments may include those persons with a mental illness or developmental disability and people suffering from Alzheimer's Disease or some other dementia. These people are at risk of being abused or neglected physically or financially. They are at risk of homelessness or are homeless. These adults, of all ages, also face the loss civil and personal rights.

IPSC was established in 1988 based on activities that have continued since 1981. IPSC is comprised of individuals and organizations from all parts of Illinois. It also represents a joint effort of aging and disability rights advocates. The IPSC is funded by grants from the Retirement Research Foundation and the Chicago Community Trust.

The Illinois Protective Service Coalition is a project of The Illinois Alliance for Aging, a statewide not-for-profit membership organization providing leadership to enable older adults in Illinois to live and work with dignity, self respect and security. The IAA is family focused and has the largest statewide membership of individuals and organizations concerned with the needs of senior citizens.



Illinois Protective Service Coalition

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INDIVIDUALS WITH A DECISION-IMPAIRMENT

A person with a decision impairment has difficulty in making or implementing critical decisions in their own best interest.

People become decision-impaired as a result of physical or mental dysfunction, abuse, neglect, trauma, substance abuse and misuse, social and economic deprivation, or a combination of these causes. Adults who have decision impairments may include those persons with a mental illness or developmental disability and people suffering from Alzheimer's Disease or some other dementia.

One distinguishing characteristic of individuals with a decision-impairment is the intensity and diversity of their needs when they encounter a service system. A second characteristic is that their impaired judgment often leads them to refuse service or to access and use services and support systems poorly. A third characteristic is that the provision of effective and appropriate services to these people often needs coordinated involvement from human service, medical and legal professionals.

Decision impairment is not a total disability. Individuals with decision impairment can benefit from a range of supportive, preventive and rehabilitative services.

Individuals with a decision-impairment and their care-givers are often found "falling between the cracks" between service systems. They are easily victimized and at great risk of becoming homeless. They also face the loss civil and personal rights.

National Guardianship Monitoring Program Can Be
Resource for Courts

Statement by Susan Miler
National Guardianship Monitoring Program
American Association of Retired Persons

Second Guardianship Roundtable Discussion
United States Senate Special Committee on Aging
Dirksen Senate Office Building
April 16, 1993

The Problem

Mrs. Thomas lived at home with her developmentally disabled adult son for whom she was guardian. Since the establishment of the guardianship both Mrs. Thomas and her son had grown progressively frail. He had become bedridden and she could no longer lift or turn him. He developed serious bedsores and she was on the verge of exhaustion. Mrs. Thomas had been told that it would be a wait of five years before her son could be placed in a local care facility.

Mr. Jones suffered a head injury as a result of a motorcycle accident. His wife was named as his guardian. After extensive rehabilitation, Mr. Jones regained most of his abilities and returned to full-time employment. He remained under guardianship.

Mrs. Smith suffered from Alzheimer's disease. At the time a guardianship was established, her daughter Joan was appointed guardian and agreed to care for her mother at home even though she was bedridden and required 24-hour supervision. Over time, this arrangement became difficult and the guardian began to leave the ward home alone for long periods of time.

Mr. Peters' son Tim had been awarded a large settlement in an accident suit. Mr. Peters was named conservator of his son's estate. A few years later, when Mr. Peters decided to start a business, he borrowed over \$30,000 from Tim's estate.

All of the vignettes described above come from reports from volunteers in the National Guardianship Monitoring Program.¹ They show some of the kinds of problems that can arise after a guardianship has been established and they illustrate the need to maintain oversight of guardianships.

Since 1988, the National Guardianship Monitoring Program has been working collaboratively with courts around the country to establish programs using older

¹ Real names have not been used.

volunteers as guardianship monitors. The impetus for the program came from the 1987 Associated Press series which was very critical of the U.S. guardianship system. Among the pervasive problems noted was a lack of resources to provide ongoing monitoring of guardianship cases. Many probate judges reported that they wanted to monitor guardianships but that they lacked the staff to follow up once a guardian was appointed for an incapacitated person. This lack of follow up meant that often cases had not been checked in many years.

The Program

Legal Counsel for the Elderly, a department of the American Association of Retired Persons, saw an opportunity to offer assistance to overburdened courts by recruiting volunteers from the AARP membership and by working with court staff to monitor cases. A demonstration project was funded by the State Justice Institute with matching funds from AARP. The program's first four sites were Atlanta, Houston, Denver, and Portland, Oregon.

AARP has developed a model volunteer guardianship monitoring program that has proven to be effective and cost efficient. For courts that are selected to participate in the program, AARP provides assistance in:

- ▶ readying the court to begin a program
- ▶ recruiting volunteers
- ▶ training of the Program Coordinator
- ▶ training of the volunteers
- ▶ furnishing materials
- ▶ providing ongoing technical assistance

AARP has also written a Handbook to provide courts with the practical information and materials they would need to establish a volunteer guardianship monitoring program. The Handbook is free of charge to courts and \$15.00 to all other interested agencies.²

Volunteers serve the courts in three roles:

1) **Court Visitors** act as the "eyes and ears" of the court. They make personal visits to the ward and guardian and, using a standard reporting form, report back to the court on the care the ward is receiving. They make recommendations for court action, when appropriate, and may assist the court in taking follow up action.

² To order a Handbook, please write: Mary Twomey, AARP/LCE, 601 E Street, NW, Washington, DC 20049 or call (202) 434-2165.

2) **Court Auditors** review the reports of guardians of the property. They scrutinize the reports for discrepancies, examine the balances, and check for adherence to guardianship law. They report any discrepancies or concerns to the court.

3) Experience from the program clearly indicated that better methods must be developed to adapt court records systems to meet the needs of monitoring. When court records were examined, it was discovered that a significant proportion of the records contained outdated and inaccurate information. In many cases the ward was found to be deceased or moved. Ongoing monitoring of cases is contingent upon being able to locate the wards. A third volunteer role was developed to update guardianship records. **Records Researchers** amend records to show updated addresses and telephone numbers for wards and guardians and to show when the wards have died, moved, or been restored. In Denver, the Records Researchers received permission from the Colorado State Judicial Office to update the guardianship records on the court's computer system.

The Program is managed on-site by a Program Coordinator who is usually a member of the court staff. Experience from the demonstration sites shows that, after an initial investment of time, the program is designed to require only about five hours per week of the Coordinator's time. AARP works with a court for a period of one-two years during which time the program becomes a permanent part of the court. The program is adaptable for courts of all sizes.

Accomplishments

Since the inception of the program in 1988, over 1,000 visits to guardians and wards have been made by volunteer Court Visitors in the four sites. Over 3,400 audits of the reports of guardians of the property have been made by volunteer Court Auditors. And, almost 2,600 guardianship records have been researched by the Records Researchers.

The volunteers have proven to be strong advocates for problem cases such as those identified above.

With the help of a Court Visitor, Mrs. Thomas' son received an emergency placement in a care facility and her other son was named as successor guardian.

The Volunteer Visitor recommended that the court terminate Mr. Jones' guardianship because he had regained his abilities. The Visitor testified at his restoration hearing and Mr. Jones' guardianship was terminated.

In two separate visits to meet with Mrs. Smith's daughter, a Volunteer Visitor discovered Mrs. Smith had been left alone. The Volunteer reported to the court and Mrs. Smith's daughter was ordered into court to show cause why she should not be removed as guardian. Mrs. Smith's daughter was ordered to apply some of the funds she received for caring for her mother toward respite care. A satisfactory arrangement for 24-hour supervision of her mother was developed.

During a review of Mr. Peters' guardian of the property report, a Volunteer Auditor discovered that Mr. Peters was using money from his son's estate for his own business. Mr. Peters was ordered into court. The court arranged a schedule of payments for Mr. Peters to reimburse his son's estate.

The Future

The program will establish several new sites in 1993. New Jersey and South Carolina have been selected as sites for an experiment to establish the program using a statewide model. In the statewide model, AARP staff will work with the states' Offices of Court Administration. AARP staff will train the staff of the OCAs to train Program Coordinators and volunteers, and to administer the program. The goal of this experiment is to institutionalize the program in many sites at once thereby conserving staff time and resources. Individual courts selected for development include: San Francisco, California; Kalamazoo, Michigan; and Canton, Ohio.

Another new development for the program involves monitoring minor guardianships. In San Francisco and Kalamazoo, the courts would like to know more about the status of children under guardianship. This intergenerational effort is an exciting evolution for the program.

This program has shown that volunteers can successfully serve as "eyes and ears" of the court. AARP is ready and willing to work with interested courts to develop volunteer guardianship monitoring programs. Interested courts should contact Mary Twomey, AARP/LCE, 601 E Street, NW, Washington, DC 20049 or telephone (202) 434-2165.

COMPARISON OF VOLUNTEER GUARDIANSHIP MONITORING PROGRAMS

Program Structure	Atlanta	Houston	Denver	Portland	Phoenix	Erie	Los Angeles	Connecticut
Volunteer roles	Visitors and Auditors	Visitors and Researchers	Visitors and Researchers	Visitors and Auditors	Visitors	Visitors	Visitors	Visitors
Job Descriptions	<p>Visitors review case files at court. Visit guardian and ward in place(s) of residence and report back to court with recommendation for action, if any. Use 7-page standardized "reporting form."</p> <p>Only one visit is made unless problem is found. Vols. pick up and return cases to court on an as-needed basis.</p> <p>Auditors do initial review of annual reports of conservators, checking for errors, discrepancies. On a standard form, rate report A, B, or C and describe problem found, if any. Turn in to Court Auditor for follow-up action.</p>	<p>Visitors role is the same as Atlanta.</p> <p>Researchers review the guardianship case files and verify or determine correct address and telephone number of guardian and ward. May find that ward is deceased, moved, guardianship terminated. This is reported to court for updating of court files.</p>	<p>Visitors role is the same as Atlanta.</p> <p>Researchers role is same as Houston with one addition. Volunteers have also learned how to use the court's computer system. Now volunteers can update court computer records to indicate status of guardianship or new information (e.g., new telephone number).</p>	<p>Visitors role is the same as Atlanta.</p> <p>Auditors review annual reports of the conservator 1) when the report is very complicated (e.g., involves stocks and bonds); 2) when the Court Auditor wants a "second pair of eyes" to review the report; 3) when an in-depth analysis of a whole conservatorship file is warranted (because of history); and 4) when reports would normally not be audited (reports "without orders").</p>	<p>Visitors role is generally the same as Atlanta, except Coordinator has received permission to take court files from the court. Files are available to volunteers at Coordinator's office.</p>	<p>Visitors role is generally the same as Atlanta. Visitors go in teams of two. Vols do not review whole case file. Court staff prepare a synopsis for their use. Use a shorter reporting form than AARP (2-3 pgs). Vols. come to court every quarter to turn in and pick up cases.</p>	<p>Visitors supplement professional investigator staff. Visit ward and fill out short report. Only problem cases are referred to the professional investigator.</p>	<p>Pilot Project. Visitors visit wards in nursing homes. Visit twice monthly. Report to program coordinator.</p>

Program Structure Continued	Atlanta	Houston	Denver	Portland	Phoenix	Erie	Los Angeles	Connecticut
Program funding	SJ/AARP	SJ/AARP. Now autonomous.	SJ/AARP. Now autonomous.	SJ/AARP	SJ grant. Sun City Community Council donates office space.	No funding. Estimate program start up cost \$100.	Foundation grants	Funding through Title III-D Older Americans Act money.
Program staffing	Coord. is full-time court employee (Judge's assistant)	Coord. is full-time court employee (Guardianship Coordinator)	Coord. is part-time court employee whose responsibilities are only to monitoring program.	Coord. is full-time court employee (Probate Supervisor)	Coord. is full-time court employee. Grant supports part-time assistant.	Coords. are full-time court employees (Law Clerk & Court Invest.) Also successful use of college interns.	Coordinator is full-time, grant funded.	Coord. is employee of SAGE Services. Divinity student will serve as intern.
Sources of recruitment	AARP membership through direct mail.	AARP membership through direct mail.	AARP membership through direct mail.	AARP membership through direct mail.	Sun City Community Council volunteer bureau.	AARP chapters	AARP membership through direct mail.	Placed articles/press releases in local papers.
Training	Two days, 6 hrs/day. Covers guardianship law and process; typical physical and mental impairments of people under guardianship, communication techniques; how to detect abuse and neglect, how to use the reporting form, ethics/confidentiality.	Same as Atlanta.	Same as Atlanta.	Same as Atlanta.	Two days, four hours per day. Speakers included: Judge, staff of Adult Protective Svcs., Court Accountant, Court Investigator.	Initial orientation followed by three more training meetings about a month apart. Speakers: Judge, Staff of Area Agency on Aging, M.D., vol. from CASA prog.	Half-day? Group training with speakers: Judge, county trainers.	Cooperative effort of the court, SAGE, and a local nursing home. Training lasts about 6 hours. Speakers include: Judge, nurse, ethicist.

Program Policies	Atlanta	Houston	Denver	Portland	Phoenix	Eric	Los Angeles	Connecticut
Notification of guardian	Guardian is notified about program and upcoming visit by letter and follow up phone call by volunteer.	Same as Atlanta.	Same as Atlanta	Same as Atlanta.	Letter sent to care facilities. No notification to guardians.	All guardians and all nursing homes received a standard letter informing them of the new program but not giving specific dates of visit.	None.	
Volunteer identification	Volunteers receive plastic I.D. cards. A court order authorizing visit is also made for each case and is carried by the vol.	Use only court order.	Use only court order	Same as Atlanta.	Use plastic picture I.D. from Superior Court.	Use plastic picture I.D. cards. Also carry letter of authorization from Judge and copy of letter to guardian.		Volunteers wear name tags identifying them as court visitors.
Volunteer reimbursement	Received funds from private non-profit foundation.	No reimbursement.	Use pre-existing mechanism & funds.	Use pre-existing mechanism and funds.		No reimbursement.	None.	No reimbursement.
Volunteer liability	Private vol. insurance through AARP.	Private vol. insurance through AARP.	Judicial and governmental immunity covers vols. Also, private vol. insurance through AARP.	Pre-existing policy covers judicial volunteers. Also, private vol. insurance through AARP.		Exploring private vol. insurance.		Rider on SAGE's current policy covers volunteers.

Saint Regis
The Saint Raphael Nursing Home

1354 Chapel Street
New Haven, Connecticut 06511
(203) 865-0505
Fax: 865-2295



December 31, 1992

David I. Tevelin, Executive Director
Richard Van Duisend, Deputy Director
The State Justice Institute
1650 King Street
Suite 600
Alexandria, Virginia 22314

Dear Sirs,

On behalf of Saint Regis, the Saint Raphael Nursing Home, I would like to familiarize you with the "Court Visitor" and "Volunteer Conservatorship" program to explain why donated funds for this program would be especially meaningful. Our long-term goal is to implement the program State-wide since there is a great need for advocates for our elderly.

It has been at least a year and a half since SAGE Services and Saint Regis in New Haven, Connecticut began discussing a program whereby volunteers would be trained and assigned to make decisions on behalf of an infirmed elderly individual who had no family. During this time Judge Lukens and the Probate Court Administration have also become involved. Through the cooperation of all three interested parties, we developed the "Court Visitor and Volunteer Conservatorship" pilot program.

Conceptually, this pilot program has two tiers. The first tier affords the interested volunteer with an opportunity to have a meaningful visitation role with the infirm elderly as a "Court Visitor". The court visitors are provided with information as to the type of individual they may be assigned to by the Court, and training on how to interact with his\her elderly client with ongoing guidance from the facility and SAGE services. The court visitor is not abandoned after the training program. There will always be resource people he\she can contact for advice or additional information. The court visitors are expected to fulfill minimal obligations including regular visitation, identification of needs, participation in the care planning process and the reporting of events to the "Conservator of Person".

The second tier of the program is the "Conservator of Person". This individual will have additional training to ensure full understanding of his\her legal role. This portion of the program has yet to be implemented, but the training curriculum has been developed. The "Conservator of Person" will have direct contact with the "Court Visitor" who will report on the resident's progress, needs, and advise on consents for treatments from the conservator.

David I. Tevelin
Richard Van Duizend
December 31, 1992
Page 2

Our first "Court Visitor" program was held on September 29, 1992. A small group of four people were trained. Since then, we have held an additional training session for another eight people. From this group of twelve court visitors, seven are currently assigned to residents within Saint Regis.

Thus far the court visitors who are coming to Saint Regis on a regular basis are reporting that the residents are happy to see them and are appreciative of the time that is spent with them. Also, some of the court visitors are adding that special touch to their visits by acknowledging the resident's birthday with a little birthday gift, or the holidays with a little gift or card. The interaction has been positive for the court visitors and residents alike.

Granted, our current group is small. However, if you could see the difference it makes to these residents to have someone visit them on a regular basis for conversation, contact, and/or involvement with activities, you would understand why this program is so important to us. So often the need for human contact is unintentionally forgotten. This is something we can change. We have the people to change it.

Please help us in making this program a success. We need your financial support to continue with the current program, and to expand it to other nursing homes in New Haven who have a greater need for the court visitors than our facility. With your help, we also hope to expand this program to nursing homes, hospitals, and private homes throughout the State of Connecticut.

Thank you for considering to fund this worthwhile program.

Sincerely,



Patricia Nargi B.S., R.N.C.
Assistant Director of Nursing and
Staff Development Coordinator

**PILOT PROGRAM
FOR
COURT VISITOR
AND
VOLUNTEER CONSERVATOR**

**COURT VISITOR
AND
VOLUNTEER CONSERVATOR PROGRAM**

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INTRODUCTION/OVERVIEW

The "Court Visitor and Volunteer Conservator" program at SAGE and Saint Regis in New Haven, Connecticut, has grown from a seed planted approximately one year ago.

Saint Regis was deeply concerned with the cumbersome and often lengthy process to obtain a "Conservator of Person" for the infirm elderly without family or friends. Conversations were then initiated with the Probate Court, and SAGE Services in an effort to find volunteers who might serve in this capacity.

As a result, with significant support from Judge Lukens, Judge Keyes, and Probate Administration, the "Court Visitor and Volunteer Conservatorship" pilot program has been developed.

Conceptually, this pilot program has two tiers. For the interested and committed volunteers, the first tier affords an opportunity to have a meaningful visitation role with the incompetent infirm elderly as "court visitor". Court visitors are provided with training and are assigned by the court. They are expected to fulfill minimal obligations including regular visitation into private homes, hospitals, and nursing homes, as well as resident assistance in nursing homes, and participation in the care planning process. The court visitors will report on a regular basis to their assigned "conservator of person".

The "Conservator of Person" represents the second tier of the program. Persons selected for this level of care will go through extensive training to ensure full understanding of their role. For the purposes of this pilot, the conservator of person will be assigned to one nursing home, and will be conservator for six to eight patients. These residents will have court visitors who will report on their progress, needs, and advise and request consents for treatments from the conservator. The conservator will be compensated for his/her work by the Probate Court Administrator.

A full description of each program component is included in this packet.

COURT VISITOR PROGRAM

EXPECTATIONS OF THE COURT VISITOR

Court visitors are the infirm elderly's link to the outside world. They are provided with special training, and are to assist the conservator of person, to act on behalf of the elderly individual. The purpose of the court visitors is to provide personal contact, and social and mental stimulation to these elderly individuals.

The minimum program requirements are as follows:

1. Introduce his\herself to the direct caregivers of the individual, the regional ombudsman, volunteers, and to the "Patient Advocate" (if applicable).
2. To make onsite visits with the resident at least twice a month. This may take place in rest homes, nursing homes, hospitals, or private residences.
3. Demonstrate effort to get to know the elderly resident, their background, and the individuals who care for them.
4. Establish and maintain a rapport, as is best able, with these elderly residents.
5. Observe and monitor the living conditions of the elderly individual.
6. Meets with the conservator at least quarterly.
7. Prepare minimal reports as necessary.
8. Attend orientation classes.

SCREENING COURT VISITOR APPLICANTS

SCREENING COURT VISITORS

Volunteers for the Court Visitor Program will complete an application, and be interviewed for the program.

Screening questions and/ or the application should address:

- * What motivates them to enter the program.
- * Indication of desire to assist the elderly individual.
- * Verbal understanding of, and the ability to meet the program requirements.
- * 18+ years of age.
- * Prior convictions or criminal record.
- * Permission to screen for prior convictions.
- * History of physical abuse.
- * Religious beliefs that might bias reporting.
- * Ability to attend the training sessions.

Date _____

COURT VISITOR TRAINING

COURT VISITOR TRAINING

1. Screening and Approval of prospective visitors:
 - a. Completion of "Application Form"
 - b. Request for references
 - c. Request for a background check
 - d. Attendance at a required training program
2. The development of a program handbook to include:
 - a. Discussion of the job description.
 - b. Chain of command as it pertains to the court visitors role.
 - c. An explanation of court proceedings and procedures.
 - d. An explanation of reporting responsibilities.
 - e. An explanation of the connection of the court visitor to the nursing home\hospital staff, conservator, Ward Attorney, and to the Probate court.
 - f. An awareness of public benefits.
 - g. Resident rights\confidentiality.
 - h. Termination of responsibilities.
3. The educational session will include #2 (above) and the following information:
 - a. Aging issues:
 1. Most commonly seen medical conditions affecting the elderly population
 2. Family involvement or lack of
 3. Description of a typical day
 - b. Review of program goals and responsibilities of court visitors:
 1. Observe and report on the resident's condition.
 2. Participant in the life of the resident.
 3. Establish a routine of visitation to build a relationship\rapport to the highest degree the resident is capable.
 4. A clear delineation of the authorities.
 - c. Residents you will most likely be visiting - diagnostic group:
 1. Dementia - an organic mental disorder characterized by a general loss of intellectual abilities involving impairment of memory, judgement, abstract thinking, and personality. The most common cause is Alzheimer's disease (see #2 below). There are other causes also, some reversible, others irreversible.
 - a. Cerebrovascular disease (multi-infarct or dementia)
 - b. Brain tumor\trauma
 - c. Central nervous system infections
 - d. Neurological diseases i.e. Parkinson's, Multiple sclerosis, etc.
 2. Alzheimer's - An irreversible senile dementia characterized by intellectual deterioration, disorganization of personality, and functional disabilities in carrying out activities of daily living (ADL's). This deterioration occurs either slowly over many years, or very rapidly over a few years. Characteristics of the disease process are:
 - a. Early stage
 1. Forgetfulness - especially recent events (short term memory)
 2. Inability to learn new information
 3. Impaired concentration
 4. Deterioration in personal hygiene

b. Progressive symptoms

1. Memory, language, motor function become increasingly impaired
2. Person becomes more physically and intellectually disabled

Points of emphasis re: Demented resident's relationship with the court visitor

1. As the disease progresses, the person requires direction in ADL's and possible full assistance in same, i.e. feeding, toileting, etc.
2. Communication may be lost.
3. Resident may exhibit emotional outbursts and is not capable of understanding or appreciating what is being done for him or the attempts of others to improve the quality of his life.
4. Court visitor's expectations of visits with the residents should not be high, keeping the above points in mind.
5. Visitation suggestions
 - a. Determine the resident's most wakeful period - (different wake/sleep patterns).
 - b. Determine when the resident is least agitated.
 - c. Determine the level of communication ability - i.e. aphasic, able to understand short, direct requests, understands some part of message missing some of intent, etc.
 - d. Use of touch, and/or music during visits.
 - e. Check with nursing regarding the resident's ability to take liquids and/or solids.
 - f. Notify nursing if the resident requires any physical assistance i.e. toileting, repositioning, transferring, etc.
- d. Types of conservators and why have one?
 1. Conservator of estate - appointed to supervise the financial affairs of an individual found by the court to be incapable of doing so for him\herself.
 2. Conservator of person - appointed to supervise an individual's affairs insuring adequate care is rendered, medical needs are met, clothing is provided, and personal belongings are cared for.
- e. Conservators of person will be making decisions regarding place of abode, consent regarding medical and rehabilitative procedures such as, but not limited to:
 1. Initiation of cardiopulmonary resuscitation.
 2. Initiation of artificial feedings.
 3. Initiation of intravenous or hypodermoclysis therapy.
 4. Purchase of resident care and comfort items (only if assets less than \$1,600), with the prior approval of the conservator of person.
- f. Ethics - A branch of philosophy which is concerned with the study of rational processes for determining the best course of action in the face of conflicting choices.
 1. A review of ethical terms
 - a. Ethical dilemma - A situation involving conflicting moral claims which involves a choice between equally unsatisfactory alternatives.
 - b. Confidentiality - A duty to safeguard the individual's right to privacy.
 - c. Advocacy - Speaking for or in support of the best interest's of the individual or the vulnerable population.
 - d. Accountability - Being answerable to one's self, the health care team, the elderly individual, the employing agency, and the court.
 - e. Autonomy - The personal liberty of action which implies independence, self reliance, freedom of choice, and the ability to make decisions.
 - f. Beneficence - The principle of doing good and preventing or avoiding doing harm.
 - g. Nonmaleficence - The duty to do no harm.
 - h. Justice - Equals should be treated equally and those who are unequal should be treated differently according to their difference.
- g. Support system for the court visitors:
 1. A coordinator to approve, assign visitors, and monitor the success of the program and serve in a supportive role to the court visitors.
 2. Establish group meetings on a regular basis (at least quarterly) with the coordinator and the conservator.
 3. Formal recognition (certificates, annual meeting).

VISITATION REPORT FORM

Court visitor: _____

Name of Client: _____

Case number: _____

Name of Home: _____

Address: _____

Deceased: _____
(date if available)_____

Unable to locate: _____

Telephone: _____

Moved: _____

Special info on client: _____

Address: _____

Approximate age: _____ Sex: _____

Telephone #: _____

Date of visit: _____ Length of visit: _____

(Please check one rating for each category and explain, if necessary)

1. Medical condition of the client: _____
(If discernible)

2. Mental condition of client: _____

3. Did client respond favorably? _____
Yes No No response

4. Level of communication: _____

5. Contact with staff: _____

6. How often would you recommend further visits?

Weekly Biweekly Monthly Quarterly 6 Months Annually

7. Are you willing to make repeat visits? ___Yes ___No

If so, how often? _____

8. Were there any conditions in the home, or needs of the client, which
should be brought to our attention? ___Yes ___No

If so, explain: _____

EVALUATION OF "COURT VISITOR" PROGRAM

1. Do you regard your advocacy role as effective? ☐ Yes ☐ No

Explain: _____

2. Do you feel the training you received was adequate to help you carry out your role? ☐ Yes ☐ No

Explain: _____

3. Do you visit your resident(s) regularly i.e. at least twice a month? ☐ Yes ☐ No

Explain: _____

4. Have you been able to establish a relationship with the resident(s) you visit? ☐ Yes ☐ No

Explain: _____

5. Do you meet regularly with the conservator of these individuals? ☐ Yes ☐ No

If so, how often? _____

6. Do you find the conservator available, and helpful to you? ☐ Yes ☐ No

Explain: _____

7. If applicable, have you participated in the resident care planning process? ☐ Yes ☐ No

If so, does it help help you carry out your role more effectively as a court visitor? ☐ Yes ☐ No

Explain: _____

8. If applicable, have staff been available to help you and answer any questions you have had? ☐ Yes ☐ No

Explain: _____

9. What suggestions would you make which would help you fulfill your responsibilities in this role?

Explain: _____

10. What changes would you recommend to improve this program?

CONSERVATOR OF PERSON PROGRAM

EXPECTATIONS OF THE CONSERVATOR OF PERSON

RECORD OF CONVICTION PERMISSION FORM FOR CONSERVATOR OF PERSON

Name: _____
 last first middle initial

Address: _____

street city state zip

Date of birth: _____ Social security number _____

Description: Race _____ Sex _____ Height _____ Weight _____
Eye color _____ Hair color _____

1. Have you ever been arrested, convicted, fined, placed on probation, or been given a suspended sentence in any court (not minor traffic) in your name or in any other name? Any conviction of a criminal offense must be disclosed on this information sheet. ____ Yes ____ No

Date	Place (city, state)	Offense	Disposition
------	---------------------	---------	-------------

If name used other than above please state: _____

2. Has your driver's license ever been revoked or suspended? Yes No

[illegible]

I certify that the above information is true to the best of my knowledge and belief. I understand and agree that any false statement or omission of material fact may cause forfeiture on my part of all rights to participate in the "Volunteer Conservator" program. I also give permission for you to verify the above information with the appropriate police authorities.

Signature

Date _____

GLOSSARY

Accountability - Being answerable to one's self, the health care team, the elderly individual, the employing agency, and the court.

Advocacy - Speaking for or in support of the best interest's of the individual or the vulnerable population.

Alzheimer's - An irreversible senile dementia characterized by intellectual deterioration, disorganization of personality, and functional disabilities in carrying out the activities of daily life. This deterioration occurs either slowly over many years, or very rapidly over a few years.

Artificial feedings - The provision of food and/or nutrients thru means other than orally.

Autonomy - The personal liberty of action which implies independence, self reliance, freedom of choice, and the ability to make decisions.

Beneficence - The principle of doing good and preventing or avoiding doing harm.

Cardiopulmonary resuscitation - The reestablishment of heart and lung action as indicated for cardiac arrest.

Cerebral vascular accident (CVA) - A disorder of the blood vessels serving the brain tissue resulting in impaired blood flow and oxygen deprivation of the brain.

Confidentiality - A duty to safeguard the individual's right to privacy.

Conservator of estate - An individual appointed by the Court to supervise the financial affairs of an individual found by the court to be incapable of doing so for himself/herself.

Conservator of person - An individual assigned by the Court to supervise an individual's affairs, other than financial, insuring adequate care is rendered, medical needs are met, clothing is provided, and personal belongings are cared for.

Dementia - An organic mental disorder characterized by a general loss of intellectual abilities involving impairment of memory, judgement, abstract thinking, and personality. There are various causes for dementia, some reversible, others irreversible.

Durable Power of Attorney (POA) for health care decisions - A document in which you name another person to make medical decisions other than the withdrawal of life support systems on your behalf should you become unable to make or communicate such decisions yourself. He or she may not make decisions regarding: (1) withdrawal of life support systems (2) withdrawal of food and fluids, and (3) medical treatment decisions designed solely to maintain your physical comfort.

Ethical dilemma - A situation involving conflicting moral claims which involves a choice between equally satisfactory alternatives.

Ethics - A branch of philosophy which is concerned with the study of rational processes for determining the best course of action in the face of conflicting choices.

Gastrostomy tube - A tube placed into the stomach, thru a surgical technique, in order to provide liquid foods, fluids, and medications, to an individual.

Health care agent - A person whom you authorize in writing to convey your wishes concerning whether you wish to withhold or withdraw life support systems. A health care agent does not act unless you are unable to make or communicate your decisions about your medical care. It is important to understand that a health care agent cannot represent your wishes on decisions other than whether to withhold or withdraw life support systems.

Hydration - The absorption of or combination of water.

Hypodermoclysis - The introduction into the subcutaneous tissues of fluids in large quantity. This method of introducing fluids into the body is used when intravenous therapy, for whatever reason, cannot be used.

Incompetent - An individual who cannot function properly and/or unable to properly manage his/her affairs.

Intravenous infusion - Administration of fluids through a vein.

Involuntary conservatorship - When an individual alleges that a person is incapable of caring for him/herself, that individual can file an Application for Appointment of Conservator in the court of probate, in the district where the alleged incapable person resides or has his/her domicile.

Justice - Equals should be treated equally and those who are unequal should be treated differently according to their difference.

Living will - A document that states whether you wish to have administered life sustaining procedures or treatment should you be in a terminal condition or permanently unconscious. A living will goes only into effect when (1) you are unable to communicate your decisions about your medical care AND (2) you are in a terminal condition or permanently unconscious.

Nasogastric tube - A tube of soft rubber or plastic that is inserted through a nostril and into the stomach. The tube may be inserted for the purpose of instilling liquid foods or other substances, or for stomach decompression.

Nonmaleficence - The duty to do no harm.

Respirator - A device which provides artificial respirations, or breathing.

Self Determination Act - Passed by Congress in 1990. This went into effect December 1, 1991. The provisions of this Act require certain health care facilities to inform adult patients of their rights to formulate advance directives for medical care in the event they become incapable of expressing their wishes concerning their medical treatment.

Temporary conservatorship - Usually appointed on an emergency basis, which may last no longer than 30 days, when it can be shown that irreparable personal or financial damage will result if appointment of a conservator is delayed for a hearing and formal notice.

Ventilator - See "respirator"

Voluntary conservatorship - Used when an individual is not legally incapable, but nevertheless would prefer another individual to handle his/her affairs. This is subject to oversight by the Court.

9. Ethics - A branch of philosophy which is concerned with the study of rational processes for determining the best course of action in the face of conflicting choices.
- a. A review of ethical terms
 1. Ethical dilemma - a situation involving conflicting moral claims which involves a choice between equally unsatisfactory alternatives
 2. Confidentiality - a duty to safeguard the individual's right to privacy
 3. Advocacy - speaking for or in support of the best interests of the individual or vulnerable population
 4. Accountability - being answerable to one's self, the health care team, the elderly individual, the employing agency, and the court
 5. Autonomy - the personal liberty of action which implies independence, self-reliance, freedom of choice, and the ability to make decisions
 6. Beneficence - principle of doing good and preventing or avoiding doing harm.
 7. Nonmaleficence - the duty to do no harm
 8. Justice - equals should be treated equally and those who are unequal should be treated differently according to their difference.
- NOTE: Some conservators will have access to an Ethics Committee which can help resolve ethical conflicts. The Court may always be asked to assist in ethical conflicts.
10. Legal Risks
- a. Volunteer conservators should be granted immunity.
 - b. Volunteer conservators can bring problems to the court for determinations.

EVALUATION OF "VOLUNTEER CONSERVATOR" PROGRAM

EVALUATION OF THE CONSERVATOR OF PERSON PROGRAM

1. Do you regard your advocacy role as effective? ☐ Yes ☐ No
 Explain: _____

2. Do you feel the training you received was adequate to help you carry out your role? ☐ Yes ☐ No
 Explain: _____

3. How often do you visit the resident(s) you conserve? _____
4. Have you been able to establish a relationship with the resident(s) you conserve?
 Explain: _____

5. Do you meet regularly with the "court visitors" assigned to these individuals? ☐ Yes ☐ No
 If so, how often? _____
6. Do you find the "court visitors" reports helpful to you in making decisions for the residents? ☐ Yes ☐ No
 Explain: _____

7. If applicable, have you participated in the care planning process?
☐ Yes ☐ No
 If so, does it help help you carry out your role more effectively as a conservator? ☐ Yes ☐ No
 Explain: _____

8. If applicable, have staff been available to help you and answer any questions you have had? ☐ Yes ☐ No

Explain: _____

9. Is the probate court supportive in helping you carry out role?
☐ Yes ☐ No

Explain: _____

10. Have you encountered ethical conflicts involving choices and/or life and death decisions? ☐ Yes ☐ No

If so, explain: _____

11. Who can you turn to for advice or help? _____

12. What suggestions would you make which would help you fulfill your responsibilities in this role?

Explain: _____

13. What changes would you recommend to improve this program?

MISCELLANEOUS

IMMUNIZATION RECORD

FROM: The Court

TO: Prospective court visitors and conservators of person

RE: Immunization documentation

Please submit the following immunization form to your physician. Upon completion, it should be returned to the agency where you are volunteering.

Dear Physician,

In an attempt to discourage the spread of childhood diseases, we require all visitors and conservators to provide documentation that they have been vaccinated for mumps, measles, and rubella.

Regarding measles vaccination, anyone born after January 1, 1957 must provide documentation of having been infected with measles, or having received their vaccination after January 1, 1969 at 15 months of age or older.

Please review the records of your patient listed below, who has applied to be a visitor or conservator, and complete this form. In the event that the vaccination records are unavailable or that the vaccinations for measles, mumps, and rubella have not been received, your patient must be vaccinated prior to beginning visitor or conservator work.

Return this form in the enclosed self addressed stamped envelope.

Patient's name: _____

Date measles vaccination received: _____

After 15 months of age? Yes ____ No ____

If no, vaccination readministered on _____

Date DPT received? _____

Date MMR received? _____

Illness with chickenpox? Yes ____ No ____

Physician's signature: _____ Date: _____

Thank you for your cooperation in this matter.

RECORD OF CONVICTION PERMISSION FORM FOR THE COURT VISITOR

Name: _____
 last first middle initial

Address: _____
 street city state zip

Date of birth: _____ Social security number _____

Description: Race _____ Sex _____ Height _____ Weight _____

Eye color _____ Hair color _____

1. Have you ever been arrested, convicted, fined, placed on probation, or been given a suspended sentence in any court (not minor traffic) in your name or in any other name? Any conviction of a criminal offense must be disclosed on this information sheet. Yes No

Date	Place (city, state)	Offense	Disposition
------	---------------------	---------	-------------

If name used other than above please state: _____

2. Has your driver's license ever been revoked or suspended? Yes No

[illegible]

I certify that the above information is true to the best of my knowledge and belief. I understand and agree that any false statement or omission of material fact may cause forfeiture on my part of all rights to participate in the "Court Visitor" program. I also give permission for you to verify the above information with the appropriate police authorities.

Signature

Date

EXPECTATIONS OF THE CONSERVATOR OF PERSON

The conservator of person will be accountable to the probate court regarding the infirmed elderly individual's condition for whom they are conservator. Utilizing the information reported by the court visitor, along with the information he/she compiles during his/her own visits, the conservator will be responsible for meeting the needs of these elderly individuals. Some responsibilities the conservator of person will be making include decisions regarding medical treatment, providing consent, and being available on an as needed basis.

The minimum program requirements are as follows:

1. Introduces his/herself to the regional ombudsman, the direct caregivers of the individual, and any other significant parties involved.
2. Makes onsite visits with the resident at least quarterly.
3. Meets with the court visitors at least quarterly.
4. Makes decisions on the elderly individuals' behalf based upon the information that is reported by the court visitors as well as from his/her own observations.
5. Reports any unusual or threatening situations to the Probate Court.
6. Prepares reports and documents for the Probate Court as necessary.
7. Attends orientation sessions.

SCREENING CONSERVATOR OF PERSON APPLICANTS

SCREENING CONSERVATORS

All volunteers for the Court Visitor Program will complete an application, and be interviewed for the program.

Screening questions and/ or the application should address:

- * What motivates them to enter the program.
- * Indication of desire to advocate for the infirmed elderly individual.
- * Verbal understanding of, and the ability to meet the program requirements.
- * 21+ years of age.
- * Permission to screen for prior criminal convictions.
- * History of physical abuse.
- * Religious affiliations which might bias reporting.
- * Attend the training sessions.

Conservators will also be encouraged to attend an optional training program module on Pastoral Care.

Date _____

CONSERVATOR OF PERSON TRAINING

1. Screening and approval for prospective conservators:
 - a. Completion of the "Application Form"
 - b. Request for references
 - c. Request for a background check
 - d. Attendance at mandatory training sessions
2. Aging issues:
 - a. Most commonly seen medical conditions affecting the elderly population
 - b. Family involvement or lack of
 - c. Description of a typical day in the facility
3. Types of conservators and why have one?
 - a. Conservator of estate - appointed to supervise the financial affairs of an individual found by the court to be incapable of doing so for him\herself.
 - b. Conservator of person - appointed to supervise an individual's affairs ensuring adequate care is rendered, medical needs are met, clothing is provided, and personal belongings are cared for.
 1. Facility expectations of the conservator of person:
 - a. Conservator will establish a relationship with the residents as best able based on trust, confidence, and good faith.
 - b. Regular visitation\availability.
 - c. Attendance at resident care planning meetings.
 2. Conservator expectation
 - a. Facility will provide a training program.
 - b. Facility will review medical record with the conservator.
 - c. Facility will provide support\consultation via care plan meetings, pastoral care, ethics committee, etc.
 - d. Conservator will receive and understand explanation of proposed medical\treatment procedures prior to being asked permission for same.
4. Types of conservatorship:
 - a. Temporary conservatorship - Usually appointed on an emergency basis, which may last no longer than 30 days, when it can be shown that irreparable personal or financial damage will result if appointment of a conservator is delayed for a hearing and formal notice.
 - b. Voluntary conservatorship - Used when an individual is not legally incapable, but nevertheless would prefer another individual to handle his\her affairs. This is subject to oversight by the court.
 - c. Involuntary conservatorship - When an individual alleges that a person is incapable of caring for him\herself, that individual can file an Application for Appointment of Conservator in the court of probate, in the district where the alleged incapable person resides or has his\her domicile.
5. Additional related duties\situations:
 - a. Chief advocate for the resident
 - b. Major medical decisions (life\death?) - may need to seek help from the courts
 - c. Active participation in the life of the resident
 - d. Review of medical records
 - e. Establish a routine of visitation to build a relationship\rapport to the highest degree the resident is capable.
 - f. Application for entitlements (available programs) for which the resident may be eligible.



STATE OF CONNECTICUT
OFFICE OF THE
PROBATE COURT ADMINISTRATOR

JUDGE RALPH D. LUKENS
ADMINISTRATOR

ATTORNEY LINDA A. DOW
CHIEF COUNSEL

ATTORNEY THOMAS E. GAFFEY
ASSISTANT TO THE ADMINISTRATOR

186 NEWINGTON ROAD
WEST HARTFORD, CT 06110
TEL (203) 566-7897
FAX (203) 566-3655

January 4, 1993

State Justice Institute
1650 King Street, Suite 600
Alexandria, Virginia 22314

Attn: David I. Tevelin, Executive Director
Richard Van Duizend, Deputy Director

Dear Messrs. Tevelin and Van Duizend:

As each year passes, with the ballooning effect of our senior citizen population, the need for more conservators (guardians in some states) steadily increases. Statistics in the State of Connecticut clearly indicate that, during the past five years, the number of persons under conservatorship has increased by more than 50%; the rate of increase is steady; and there is no sign of abatement.

Bar Associations, State Departments of Aging or Human Resources, and the states themselves, have spent a great deal of time and money attempting to supply the courts with conservators for this aging population. It has become obvious that a new, innovative program is needed to fill the steadily increasing gap between the number of people the courts and their wards need and the numbers of people available.

Sage Services of Connecticut, Inc. has conceived and initiated a pilot program designed to narrow or reduce the gap. Without funding, however, that program will not survive. The project on which Sage has embarked is aimed at demonstrating that volunteers can and will fill the needs of the courts with a steady supply of conservators for the foreseeable future. The basic concept is to train volunteers to visit persons over whom the court has appointed conservators and to then encourage--but not require--those court visitors to become conservators themselves.

As the Probate Court Administrator of the State of Connecticut, it is my duty to oversee the 133 probate courts in the State of Connecticut. It was quite by chance that I became aware of Sage's interest in working to solve what it felt was a local problem. Our statistics clearly indicate that the problem is not a local problem; not a statewide problem; but a nationwide problem. While Sage may not be able to solve the nationwide problem, there are already clear indications that it will be able to demonstrate a clear and convincing program to solve the real problem which exists in the probate courts of the State of Connecticut.

I am quite familiar with several of the guardianship/conservatorship monitoring programs throughout the country as a result of my involvement as a consultant to the State Justice Institute Project on Conservatorship Guardianship Monitoring, University of St. Louis, Missouri. I also served as a panelist at the National Conference of Chief Justices Committee on Guardianship and Conservatorship in Scottsdale, Arizona; as a roundtable member of the U.S. Senate Special Committee on Aging, Washington, D.C.; as a member of the AARP Legal Counsel for the Elderly Guardianship Monitoring Coordinators Conference, Washington, D.C.; and most recently as a discussion leader at the National College of Probate Judges Annual Seminar in New Orleans, Louisiana. The latter involved three lecture-discussion sessions on guardianship monitoring and a luncheon workshop arranged at my request for the sole purpose of gathering information on what is available in the guardianship/conservatorship monitoring area nationwide.

- g. Termination of conservatorship:
 - 1. Upon the death of a resident
 - 2. If the ward has been restored to mental capacity and requests in writing the conservatorship be terminated.
 - 3. Every 3 years, the court reviews each conservatorship to determine appropriateness.
 - 4. The facility has the right to review the conservatorship to ensure the volunteer is acting in the resident's best interest.
 - 5. The conservator resigns and such resignation is accepted by the Court.
- 6. Review of medical conditions which will most likely require an individual to have a conservator:
 - a. Dementia
 - b. Alzheimer's disease
 - c. Cerebrovascular disease (multi-infarct or cerebrovascular accidents)
 - d. Brain tumor\trauma
 - e. Central nervous system infections
 - f. Neurological diseases i.e. multiple sclerosis, Huntington's chorea, Parkinson's, etc.
- 7. Advance directives - (Use video and prepare sample packs)
 - a. "Self-Determination Act" - Passed by Congress in 1990. This went into effect December 1, 1991. The provisions of this Act require certain health care facilities to inform adult patients of their rights to accept or refuse medical treatment, and of their rights to formulate advance directives for medical care in the event they become incapable of expressing their wishes concerning their medical treatment.
 - b. Access to advance directives information by the conservator.
 - 1. Living Will - A document that states whether you wish to have administered life sustaining procedures or treatment should you be in a terminal condition or permanently unconscious. A living will goes only into effect only when (1) you are unable to make or communicate your decisions about your medical care AND (2) you are in a terminal condition or permanently unconscious.
 - 2. Health Care Agent - A person whom you authorize in writing to convey your wishes concerning whether you wish to withhold or withdraw life support systems. The agent does not become involved in any other treatment decisions. A health care agent does not act unless you are unable to make or communicate your decisions about your medical care. It is important to understand that a health care agent cannot represent your wishes on decisions other than whether to withhold or withdraw life support systems.
 - 3. Durable Power of Attorney for Health Care Decisions (POA) - A document in which you name another person to make medical decisions other than the withdrawal of life support systems on your behalf should you become unable to make or communicate such decisions yourself. He or she may not make decisions regarding: (1) withdrawal of life support systems (2) withdrawal of food and fluids; and (3) medical treatment decisions designed solely to maintain your physical comfort.
- 8. Proposed medical interventions (care or procedures requiring consent or refusal of conservator). To discuss the advantages and disadvantages of each as well as examples of situations which may arise.
 - a. Initiation of artificial hydration\nutrition
 - b. Initiation of intravenous therapy or hypodermoclysis therapy
 - c. Initiation of cardiopulmonary resuscitation

Unlike the other programs that have been designed primarily to monitor the conservator's or guardian's obligations to the ward, as well as the care given the ward, the Sage program is a hands-on demonstration of the ability of court visitors to assist the courts and the already appointed conservators on a much more frequent basis and to attend to the needs of persons who have no family or friends or whose families have failed to provide the continuing companionship particularly important to the frail elderly. While a program such as that designed by Sage would appear to be a social obligation of a town, county or state rather than an obligation of the judicial system, the Associated Press articles published in 1987 captioned "Guardians of the Elderly: An Ailing System", clearly placed the blame upon the courts. The proposed federal legislation which was prompted by that series of articles also clearly placed the burden of solving the problem with the courts.

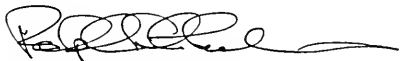
I am convinced that "monitoring" the performance of the conservator or the condition of the ward on an annual basis--or even on a semi-annual or quarterly basis--will not solve the problems which the Associated Press articles indicated exist. But even if that type of sporadic monitoring could solve the actual abuses which occurred, it certainly cannot solve the insidious abuse of merely abandoning or ignoring a person--leaving that person with no outside contact with the world except for the paid caregivers whose duty it is to provide only basic needs such as food, water and shelter. If the program which Sage is initiating is successful, it will enable the Probate Courts of Connecticut to function more effectively in providing for wards of the court. It will serve as an example to be shown to courts nationwide, as well as to Congress, of a court sponsored and shared program which meets substantial and increasing community needs.

Because of our conviction of the need and viability of the Sage program, the Probate Assembly, which is the statutory body made up of the 133 Probate Courts in Connecticut, has appointed a committee of judges to cooperate with this office and with Sage to work on this program. Unfortunately, we are a totally statutory court system and cannot privately fund such work. Our contribution is, therefore, limited to advice and the training of persons, whom Sage produces, to become court visitors, and, in some instances, court conservators.

The value of this program is difficult to put into words. Because the placing of court visitors involves a strong attempt to match the background of the visitor with that of the ward, the program encourages participation from people of all ethnic, racial, cultural and economic backgrounds. I was fortunate to have been a participant in the first two training sessions. To see the mix of people who were willing to donate their time and talents was heartwarming. The volunteers obviously came from all walks of life and are willing to help people who come from all walks of life.

The Probate Court System in the State of Connecticut fully supports the efforts of Sage; first because the program will improve the lives of the recipients of Sage's efforts; and second because the program will be extremely beneficial in helping the Connecticut Probate Courts to carry out their duties.

Sincerely,



Ralph D. Lukens
Probate Court Administrator

RDL/kc

Yale University

School of Medicine
Program on Aging
45 College Street
New Haven, Connecticut 06510
Telephone: 203 785-7178

Lisa F. Berkman, Ph.D.
Co-Director

Mary E. Tinetti, M.D.
Co-Director

Joanne M. McGloin, M.Div., M.S.
Associate Director

January 4, 1993

Mr. Lou Zaccaro
Executive Director
Sage Services of Connecticut, Inc.
701 Whitney Ave.
New Haven, CT 06511

Dear Lou,


I am writing in support of your application to the State Justice Institute for funding of the Court Visitor/Conservator of Person Program. The aim of this program, to recruit, train and place volunteers in service to indigent nursing home residents, addresses a serious and growing need throughout our state, particularly in its cities.

Sage can boast of significant accomplishments to date in the development of this program: the establishment of working relationships with State agencies, especially the State Department of Aging, as well as the Probate Court Administration, individual courts and nursing homes; the development of community resources including a training manual, an advisory committee, an ethics panel, and successful recruiting strategies; and the procurement of seed money from both public and private sources.

The Yale Health and Aging Project, a longitudinal, prospective health study of nearly 3,000 elderly New Haven residents, over several years of observation found that lack of social support and presence of cognitive impairment were strong predictors of nursing home admission. It is no wonder then that area nursing home administrators have identified the lack of qualified and interested persons to act as conservators as an acute need in facilities. As the elderly population continues to grow, the number of persons who are without social and financial assets will, unfortunately, increase as well. The program will help to ameliorate isolation and suffering among these frail elders.

You have my best wishes for the success of this program. Please do not hesitate to call if I can be of any further assistance.

Sincerely yours,


Joanne M. McGloin
Associate Director
Program on Aging



Sage Services of Connecticut, Inc.

703 Whitney Avenue • New Haven, CT 06511 (203) 777-7401

"With and For Older People"

A United Way Agency and an associated organization of
the Downtown Cooperative Ministry

RECEIVED JAN 6 1993

January 6, 1993

State Justice Institute
1650 King Street, Suite 600
Alexandria, Virginia 22314

Attn: David I. Tevelin, Executive Director
Richard Van Duizend, Deputy Director

Gentlemen:

Enclosed please find a concept paper/grant application for a Court Visitor/Conservator of the Person Program. We are requesting less than \$40,000 and seeking an application waiver.

Additionally, we are seeking a good cause waiver of the submission deadline specified in Section VID. The support letter from Judge Ralph D. Lukens, State of Connecticut Probate Court Administrator, clearly defines the significant benefit to the State Courts that this project would produce. With the interest of the State Department of Aging along with the State Probate Court Administrator, this Demonstration Project takes on the added benefit of providing a proven product for replication statewide and having nationwide capability.

I would take the liberty to point out that Sage Services, along with the Probate Court Administrator and Saint Regis Health Center has developed and implemented a pilot program for this project and Sage Services has secured the funding for that phase. The Demonstration Project will be an expansion and enhancement of the Pilot Program benefitting from the experience gained during this phase of the Court Visitor/Conservator of the Person Program.

You are welcome to contact Judge Lukens or me, should you have any questions or require any further information regarding this concept paper depicting a most innovative program.

Sincerely,

Louis Zaccaro
Executive Director

LZ/cks
Enclosures

"COURT VISITOR/CONSERVATOR OF THE PERSON PROGRAM"

THE PROGRAM NARRATIVE

i. Why this project is needed and how it will benefit State courts?

During the past five years the number of elderly persons under conservatorship in Connecticut has increased by more than 50%. According to Judge Ralph D. Lukens, Administrator of the State of Connecticut, Office of the Probate Court Administrator, "the rate of increase is steady, and there is no abatement."

The Connecticut State Department of Aging, the Connecticut State Department of Human Resources, and the Connecticut Bar Association have invested an enormous amount of time, effort and money to supply the courts with conservators for this growing aging population. To date, there continues to be a gap between the number of people needed to serve as conservators and the number of aged persons needing those services.

Sage Services of Connecticut, Inc., the Connecticut State Probate Court Administrator, and Saint Regis Health Center have developed an innovative Pilot Program, currently operated by Sage Services, that trains volunteers to become court visitors to wards of the court. The court visitors are responsible to court appointed conservators of the person. When appropriate, some of the court visitors will be trained to become conservators.

The Pilot Project has demonstrated the enthusiasm of volunteers from diverse backgrounds to serve in the capacity of court visitors. The Pilot Project extending from October 1, 1992 - March 31, 1993, serves three nursing homes in the Probate Districts of New Haven and Hamden, and will involve 25 volunteers with 25 wards of the court.

ii. What will be done if the grant is awarded?

The proposed Demonstration Project will include 6 Probate Districts: New Haven, Hamden, West Haven, Woodbridge, North Haven, and the Lower Naugatuck Valley. Fifty Court Visitors will be trained and assigned to visit wards of the court with no families, who reside in nursing homes, hospitals or private homes. The second tier of the Court Visitor/Conservator of the Person Program is designed to train qualified Court Visitors to become Court appointed Conservators of the Person. The

continuing recruiting, training and coordination that Sage Services will provide to maintain the Court Visitor/Conservator of the Person Program will facilitate the ability of the court to meet the increasing need for conservators of the person for the aged population, as well as the benefit of meaningful visitation to wards of the court in human terms.

Sage Services, with the Connecticut State Department of Aging and the State of Connecticut, Office of the Probate Administrator are discussing the development of a concept to allow the Court Visitor/Conservator of the Person Program to be replicated statewide.

The Grant period for the Demonstration Project is one year.

iii. How the effects and quality of the project will be determined?

The project will be evaluated by Court Visitors, the Conservators of the Person, the Advisory/Ethics Committee, the Ad-hoc Planning Committee, the Program Planning and Evaluation Committee of the Sage Services Board of Directors, and the Sage Services Board of Directors.

The Court Visitors and Conservators of the Person will be asked to complete monthly visitation reports. The Advisory/Ethics Committee will determine that ethical standards are being met, and forward their reports to the Ad-hoc Planning Committee. The Ad hoc Planning Committee will review summaries of visitation reports, and Advisory/Ethics Committee reports, and make recommendations for enhancement of the project to the Program Planning and Evaluation Committee of the Sage Services Board of Directors. The Program Planning and Evaluation Committee will evaluate the effectiveness of the Demonstration Project and make recommendations to Sage Services Board of Directors. The Sage Services Board of Directors will set policies and insure grant criteria for the program are being met. The Executive Director will be responsible for the day-to-day operation of the program, insuring that Board directives, policies, and grant criteria are being met. A committee of representatives of all of the above bodies and the staff of Sage Services will be convened to develop a final Evaluation Report on this Demonstration Project.

iv. How others will find out about the project and be able to use the results?

The grant will enable Sage Services to produce two video tapes. One will be used for training court visitors and conservators of the person; the second will be available to the court system and the Connecticut State Department of Aging for those interested in program replication.

Public awareness will be developed by media releases and networking with groups such as the Connecticut Coalition on Aging. Press releases of the Demonstration Project will appear in Connecticut Life, a newspaper that reaches 30,000 older people. (The February Connecticut Life will carry a story about the Pilot Project of the Court Visitor/Conservator of the Person Program, and will do a follow-up on the Demonstration Project.) Sage Services will distribute a special Newsletter to Sage Services mailing list of 5,000 older persons. A member of the Sage Services Board of Directors is President of a New Haven Community Access Cable Television Station. He is interested in producing a documentary and panel discussions of the Demonstration Project of the Court Visitor/Conservator of the Person Program for distribution to community access television stations. Copies of the final Demonstration Project Evaluation Report will be made available to parties expressing interest in program replication.

FORM E

State Justice Institute

Concept Paper Preliminary Budget

Personnel	\$ <u>69,396</u>
Fringe Benefits	\$ <u>2,670</u>
Consultant/Contractual	\$ <u>10,350</u>
Travel	\$ <u>750</u>
Equipment	\$ <u> </u>
Supplies	\$ <u>500</u>
Telephone	\$ <u>720</u>
Postage	\$ <u>580</u>
Printing/Photocopying	\$ <u>700</u>
Audit	\$ <u>600</u>
Other Office Rent	\$ <u>6,747</u>
Volunteer Training Costs	
Indirect Costs (%)	\$ <u> </u>

PROJECT TOTAL	\$ <u>93,013</u>
CASH MATCH	\$ <u>3,250</u>
IN-KIND MATCH	\$ <u>50,300</u>
AMOUNT REQUESTED FROM SJI	\$ <u>39,463</u>

Financial assistance has been or will be sought for this project from the following other sources:

Yale Divinity School, New Haven, Ct.

New Haven Foundation, Woodbridge, Ct.

1st Church of Christ, Woodbridge, Ct.

BUDGET NARRATIVE

1. Justification of Personnel Compensation

Executive Director: Pro-rated at 10% of \$32,000 Annual Salary (\$3,200 budgeted) - To oversee program operation, program finances, and insure program meets all requirements of funding sources.

Program Coordinator: 16 hours per week @\$13 per hour (\$10,816 budgeted) - To coordinate all aspects of program operation, enlist volunteers, match volunteers and wards of the state, schedule training and prepare all necessary reports.

Administrative Assistant: Pro-rated at 10% of \$20,800 Annual Salary (\$2,080 budgeted) - To track volunteer hours, type reports, coordinate visits of volunteer court visitors with wards of the court.

Yale University Divinity Student Intern: Full amount of contribution toward intern's stipend (scholarship) requested by Yale. (We are applying for a \$1,500 subsidy as indicated in the Cash Match.) (\$3,000 budgeted) - To assist in areas of public awareness and outreach; (i.e churches, professional and service organizations.)

Volunteers: Please see in-kind section.
(\$50,300 budgeted)

2. Fringe Benefit Computation

Computed at 14% of salary costs to cover employee Federal and State Taxes, Health and Hospitalization Insurance, Unemployment Compensation, and Workman's Compensation. Percentage calculated on basis of auditor's recommendation.
(\$2,600 budgeted)

3. Consultant/Contractual Services

Bookkeeper: Pro-rated costs of \$3,900 Annual bookkeeping costs. (\$350 budgeted) - To track expenditures, employee time, disburse checks, and issue monthly financial reports of program.

Media Specialist: Calculated at hourly rate of \$250 for 40 hours. (\$10,000 budgeted) - To develop and produce two videos.

- 1) Video for volunteer training purposes.
- 2) Program overview video to show funding sources and agencies interested in program replication.

4. Travel

Program travel estimated at 3,000 miles @.25 per mile as per Sage Services Personnel Policies.
(\$750 budgeted) - Staff travel to nursing homes, hospitals and private homes of wards of the state. Travel costs also include mileage to meetings related to the Court Visitor Program.

5. Equipment - Not Applicable

6. Supplies

Amount based on estimate of supplies required for similar program usage for one year.
(\$500 budgeted) - Office supplies needed for program coordination, recordkeeping and reporting.

7. Construction - Not Applicable

8. Telephone

Annual telephone costs for Sage Services are \$3,000 for phone line service. 15% of service cost assigned to Court Visitor Program. (\$450). \$270 assigned for interstate and intrastate calls. (\$720 budgeted).

9. Postage

Estimate based on 2,000 units of Project related mailings @ .29 per unit. (\$580 budgeted).

10. Printing/Photocopying

Estimate based on pro-rated costs of printing agency newsletter that advertises program. Newsletter costs \$3,120 annually, 10% of cost allocated to Court Visitor Program. (\$312 annually) Photocopying estimated on similar program usage. 6,000 copies @ .065(\$388 annually). (\$700 budgeted).

Audit

Estimate based on pro-rated \$3,500 annual agency audit costs. (\$600 budgeted)

Other

1) Rent

Estimate pro-rated @ 15% annual office rent of \$11,650. (\$1747 budgeted)

2) Volunteer Training Costs

Estimate based on Training Supplies and Materials; Fees for Health Care presenters on aging process; Fees for Legal presenters on legal aspects of program. (\$5,000 budgeted)

11. Indirect Costs - Not Applicable

12. Match

<u>SOURCE</u>	<u>AMOUNT</u>
Cash Match: 1) Yale Divinity School Grant to cover 50% of Student Intern Fee	\$ 1,500
2) First Church of Christ, Woodbridge, Ct.	1,000
3) New Haven Foundation	750
TOTAL CASH MATCH	\$ 3,250
In-Kind Match: 1) Court Visitors - 100 volunteers @ \$15 per hour x 2 hours per month x 12 months	36,000
Ad hoc Planning Committee - 20 members @\$25 per hour x 2 hours per meeting x 6 meetings annually	6,000
Sage Services Board of Directors - 24 members @\$25 per hour x 6 hours of financial and programatic review annually	3,600

Budget Narrative (continued)

Program Planning and Evaluation Committee of Sage Services Board of Directors-
5 members @\$25 per hour x 4 hours annually 500

Advisory/Ethics Committee for Court
Visitor/Conservator of the Person Program-
5 members as follows:

Attorney	@\$200 per hour
Physician	@ 250 per hour
Psychiatric Nurse	@ 100 per hour
Minister	@ 50 per hour
Eldercare Medical Research Director(Yale University)	@ 100 per hour

\$ 700 per hour

\$700 x 1 hour x 6 meetings
annually 4,200

Total In-Kind Match: \$50,300

Cash Match will be documented on a monthly basis. (Upon approval of this grant, sample forms to track in-kind match will be requested.)

State Justice Institute

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March 26, 1993

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Executive Director

RICHARD VAN DUIZEND
Deputy Director

Louis Zaccaro
Executive Director
Sage Services of Connecticut, Inc.
703 Whitney Avenue
New Haven, Connecticut 05511

Dear Mr. Zaccaro:

Thank you for submitting the concept paper entitled "Court Visitor/Conservator of the Person Program" (No. C-93-190). Your paper has been reviewed by the Institute staff and the Board of Directors.

The Institute received over 300 concept papers requesting more than \$40 million, a sum approximately seven times greater than the amount available for grants in this round of funding. Thus, the Board could approve grants or invite formal applications based on only those papers that demonstrated the greatest promise of improving the quality of justice across the nation. It sought to identify potential projects that would test innovative approaches to current problems and provide solutions that could be applied in many jurisdictions.

I am sorry to inform you that your paper was not selected for further consideration at this time. Among the concerns and questions raised during the review process were:

1. What were the results of pilot project evaluation and what is the difference between the pilot project and the proposed "demonstration" project?
2. What outreach techniques would be used to recruit court visitors; what criteria would be used for their selection and how would the volunteers work with the court? Would there be any costs associated with volunteer training?
3. Could provisions be made for an independent evaluation of the proposed project?
4. What would be the length of the videos?
5. How would the program be supported after the end of the grant period?
6. Given that many other States use volunteers as court visitors, would the Connecticut courts serve as the applicant so that the proposal could be considered as a single jurisdiction project under Section II.C.1. of the Grant Guideline?

The Board and staff greatly appreciate the obvious time and effort that went into the preparation of your paper. I hope that the decision not to invite you to submit an application does not deter you from submitting concept papers in the future.

If you have questions concerning the review process, please feel free to contact me or Richard Van Duizend, the Institute's Deputy Director. Thank you again for your interest in the SJI program.

Sincerely,

David I. Tevelin
David I. Tevelin
Executive Director

DIT:mss

cc: The Honorable Aaron Ment
The Honorable Ralph Lukens

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